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**Understanding informal caregivers' use of assistive technologies in
Mexico during their dementia caregiver experience.**

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Abstract

Dementia is a long-term progressive condition with no cure that is considered to be a major public health priority worldwide. Currently, 60% of people with dementia (PwD) reside in low- and middle-income countries (LMICs) and by 2040 the number will increase to 71%. Families from these countries are being overwhelmed by the increased numbers of cases as the depleted health infrastructures and lack of governmental support mean that families have to rely on informal caregivers (ICs) to provide essential support and care. By 2050, Latin American countries, such as Mexico and Brazil, will experience an increase of >400% in the number of dementia cases. The World Health Organization (WHO) stated in 2017 as part of their “Global action plan on public health response to dementia” that culture- and community-specific approaches need to be developed and implemented in LMICs. They argued that this need emerged from the results of various studies on LMICs that showed how each country interpreted dementia differently. Cultural interpretations have been shown to influence the dementia caregiving experience directly. However, only few studies have been conducted about ICs of PWDs from LMICs. Hence, the need to understand the complexities of the dementia caregiver’s experiences within LMICs.

In-home technologies, such as Assistive Technologies (ATs), have been shown to be effective in dementia care to improve the quality of life of the PwD and alleviate the IC’s caregiver burden. However, only a few studies have evaluated the usefulness of ATs in LMICs and no research has been conducted on the experiences of ICs with ATs in LMICs.

This thesis explores the lived experiences of ICs of PwD in Mexico, a country in which ATs are used as part of their caregiving role. The study adopted a phenomenological approach, the aim of which was to understand the role and impact of ATs in the caregiving role and caregiving experience. Nine ICs of PwD in Mexico participated in in-depth semi-structured interviews. The data were analysed using interpretative phenomenological analysis (IPA) in two parts: an idiographic analysis of the first-person accounts of each participant and a cross-case analysis that examined the convergences and divergences of their experiences across the group.

The findings from the study revealed that, to a certain extent, all of the participants went through five stages during their lived experiences as caregivers. The ICs subconsciously divided the lengthy path of their caregiving experiences into two phases: pre-AT usage and AT usage. The stages were established as: 1) emotional triggers; 2) avoidance; 3) personal values assessment; 4) self-forgiveness; and 5) acceptance (i.e., of the disease). During the pre-AT usage phase (stages 1-4), participants attributed a combination of different negative feelings and double caring responsibilities as the factors that motivated them to acquire an AT and care for their own well-being, as well as that of the PwD. It was revealed during the second stage, the AT usage phase (stages 4-5), that the ICs’ interactions with ATs were complex. On the one hand, the participants concentrated on testing, accepting and appropriating the AT to fit their own needs. On the other hand, it was revealed that ATs mediated the experience and, as a consequence, influenced the ICs’ roles and caregiver experiences.

This thesis provides a new, and in-depth, understanding of some of the complexities that derive from the dementia caregiver's experience in Mexico, an LMIC. It also provides an insight into the human-technology relationship that develops from daily interactions with the AT and how it influences the essence of the caregiver experience. Recommendations are made for designers and developers of ATs for use in the care of PwD based on the findings from this study.

Keywords: dementia, informal caregivers, phenomenology, Interpretative Phenomenological Analysis, technology-mediated experience, assistive technologies, Mexico

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List of Acronyms

AAL	Ambient Assisted Living
AD	Alzheimer's disease
ADL	Activities of Daily Living
AI	Artificial Intelligence
AT	Assistive Technology
BPS	British Psychological Society
BPSD	Behavioural and Psychological Symptoms of Dementia
CAS	Caregiving Ambivalence Scale
FEDEMA	Mexican Federation of Alzheimer's
GDP	Gross Domestic Product
GNI	Gross National Income
GPS	Global Positioning System
GSM	Global System for Mobile
GTM	Grounded Theory Method
HIC	High-income country
IADL	Instrumental Activities of daily living
IAT	Intelligent Assistive Technology
IC	Informal Caregiver
IMSS	Instituto Mexicano del Seguro Social (Mexican Social Security Institute)
IoT	Internet of Things
IPA	Interpretative Phenomenological Analysis
ISSSTE	Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado
LMIC	Low-and-Middle-Income Country
ML	Machine Learning
PwD	People with Dementia/Person with Dementia
USA	United States of America
WHO	World Health Organization

Chapter 1: Background of research

1.1 Introduction

This thesis explores the lived experiences of informal caregivers (ICs) of people with dementia (PwD) who use assistive technologies (ATs) at home in Mexico. Dementia is considered a public health priority worldwide (World Health Organization, 2012). Low- and middle-income countries (LMICs), such as Mexico, are particularly affected by this situation since their depleted health infrastructures and lack of governmental support drives families to rely on their ICs (Alzheimer's Disease International, 2016). Martinez-Alcalá et al. (2015) suggested that in most LMICs, when a family member is diagnosed with dementia, it is highly likely that someone from their own family will assume the role of IC. In the case of Mexico, it has been speculated that this tradition stems from the influence of their cultural values (Arévalo- Flechas et al., 2014). However, little is known about how cultural values or any other factor influences the dementia caregiving experience of Mexicans and carers from other LMICs.

In high-income countries (HICs), assistive technologies (ATs) have been shown to enhance the patients' and caregivers' quality of life (Astell et al., 2019). This attribution stems from how ATs have the potential to support or complement physical (i.e., prevention of wandering, medicine management, fall prevention) and cognitive (i.e., orient, remind, communicate and alert) deficits of PwD (Jotterand et al., 2019). Two of the most common goals of these devices are to ensure the safety and security of the PwD (Gibson et al., 2019). ATs have the potential to maintain or increase the PwD independence and autonomy at home, since the devices can help to reduce the need to be in close proximity at all times to the PwD (Sriram et al., 2020). It has been suggested that the benefits of ATs extend to their caregivers because by increasing the PwD security and safety at home, the caregivers' responsibilities are considerably reduced, thereby alleviating their stress and delaying institutionalisation (Beaudoin et al., 2020).

Only a few studies have evaluated the usefulness of ATs in LMICs and no research has been conducted on the experiences of ICs with ATs in LMICs. In this research, there is a specific focus on how ATs are incorporated into the caregiving role and the impact the piece of technology has on the IC and the caregiving experience. This thesis also investigates the beliefs, thoughts, and feelings that influence ICs' decision to acquire ATs and their opinions about the technology. The results therefore provide a useful insight into the lived experiences of ICs of PwD regarding their use of ATs that may be useful to designers and developers of ATs to create better technologies and to policymakers to provide appropriate support interventions and training for ICs.

This chapter is divided into various sections. Section 1.2, provides an outline of the research context with the main concepts that will be used throughout the thesis. Section 1.3 contains a description of the problem statement. Sections 1.4 and 1.5 delineate the research question and objectives of the investigation respectively. Section 1.6 provides an outline of the different chapters of the thesis.

1.2 Research Context

The aim of this section is to provide a holistic picture of the different domains that pertain to this investigation. The following concepts and descriptions will set the scene for the following chapters. The discussion is concentrated on four main areas: section 1.2.1 contains a definition and description of the most common types of dementias; section 1.2.2 provides a brief overview of Mexico, the setting of this study, and the estimated cases of people living with dementia; section 1.2.3 is a description of informal caregiving and the current situation of ICs in Mexico; in section 1.2.4, some unique particularities of Mexico are outlined; and section 1.2.5 is an explanation of the nature of ATs.

1.2.1 Dementia

In 2012, the World Health Organization (2012) declared dementia as a public health priority and “the leading cause of dependency and disability among older adults in both high-income countries and LMIC” (p.8). Low-income countries are those with a gross national income (GNI) per capita of \$1,025 or less and middle-income countries have a GNI per capita of between \$1,026 and \$12,375 (The World Bank, 2020). As of 2019, Alzheimer’s Disease International (2019) reported that the estimated annual cost of dementia is \$1 trillion and that, by 2050, this figure will double. Currently, 60% of people with dementia (PwD) reside in LMIC and by 2040 the number will increase to 71% (World Health Organization, 2018). By 2050, Latin American countries, such as Mexico and Brazil, will experience an increase of >400% in the number of dementia cases (Alzheimer’s Disease International & Bupa, 2013). Meiland et al. (2017) stated that “dementia is one of the most important contributors to dependence, disability, and care home placement” (p.2). Thus, dementia is disease not only for the family but also for society, as it challenges health systems due to the increase in cases (World Health Organization, 2012).

Dementia is a set of associated symptoms that indicate a progressive decline of a person’s cognitive functions (World Health Organization, 2012). The Diagnostic and Statistical manual of mental disorders (DSM-V) suggests that almost all mental disorders present cognitive impairments, to some extent at least. However, in other conditions such as bipolar disorder and/or

schizophrenia, the cognitive decline develops from birth or at a young age, in contrast to dementia, which affects cognition later in life (American Psychiatric Association, 2013). Furthermore, due to progress in medicine, the concepts of dementia and mild cognitive impairment, were changed to major and minor neurocognitive disorder respectively (American Psychiatric Association, 2013). This change was rooted in evidence that suggests that not all subtypes of dementia start with forgetfulness as the first symptom, such as the case of frontotemporal dementia that commence with speech impediments (Büla, 2019). In the DSM-V (American Psychiatric Association, 2013) manual, the following criteria must be met to diagnose dementia:

- 1) A progressive cognitive decline in a person with a previous level of performance that is evident in two or more cognitive domains such as, but not limited to memory loss, confusion, constant misplacing of objects, behavioural changes, verbal decline, and wandering
- 2) Evident changes and deficits in a person's everyday activities and independence. For example, forgetting payments, placing objects in strange locations, not being able to dress, and so forth.
- 3) Evidence that cognitive impairments do not occur during hallucination episodes.
- 4) An indication that the cognitive decline is not a manifestation of another mental disorder (e.g. bipolar disorder).

According to the Alzheimer's Society (2015), there are three stages for dementia: early, middle, and late. They explained that even though the identification of pre-defined stages provides some guidelines for families about what to expect, dementia is so dynamic that stages may overlap and symptoms may be more predominant in some patients. The patient's deterioration can be progressive or accelerated, and there are no stipulations regarding the time frame. The manifestations vary from disease to disease, as it worsens with time, with its progression varying from one person to another (Moody & Sasser, 2011). Specialised professionals can determine the stage of dementia from a patient using tools such as the Clinical Dementia Rating scale and the Mini-Mental State Examinations (Yuan et al., 2020).

The characteristics of the early or mild stage are "minor changes in the person's abilities or behaviour" (Alzheimer's Society, 2015, p. 4). This includes changes in mood, forgetfulness, slowness of thinking, and confusion. These symptoms appear to be connected to the patient's awareness of their own cognitive deterioration, which leads to frustration, depression and/or anxiety (Klimova et al., 2015). At this stage, the PwD can still live independently and institutionalisation is not advised (Petersen et al., 2014).

Middle or moderate stages are when the patient needs assistance for their activities in daily life. Examples of this stage are: needing constant reminders for meals, medicines, and addresses as well as assistance with toileting and dressing (World Health Organization, 2012). This phase is the longest out of the three stages (e.g. it can last from 2-10 years) and it is characterised by the patient's speech impairment as they find it difficult to communicate and express their own thoughts (Kilmova et al., 2015). This stage is considered dangerous, as it is the phase in which patients can pose a risk to their lives and others' lives by doing things such as leaving the domestic gas supply on, wandering outside the house, and taking more medicine than needed. This is also the stage in which patients may experience hallucinations and/or display paranoid behaviours (O'Brien et al., 2020).

The final stage is the severe or late stage, in which a PwD becomes completely dependent as; their physical body weakens and they are bound to a bed or a wheelchair (Alzheimer's Society, 2015). The PwD finds that other people and objects are difficult or impossible to recognise and there is speech loss with pronounced episodes of emotions such as anger, sadness, and frustration (Kilmova et al., 2015). Due to the severity of their cognitive decline at this stage, the PwD will require a skilled professional to assist their caring needs at home or in a specialised nursing home (Tanaka et al., 2020).

Day (2020), explained that there are different types of dementias and they are classified as irreversible and potentially reversible. He stated that they are irreversible when the cause is degenerative brain disease. Reversible dementias can be caused by depression, a deficiency in vitamin B12, hypothyroidism, hyperparathyroidism, infectious diseases, endocrine dysfunction, toxic-metabolic disturbances, medications, untreated sleep disorders, subdural hematomas, brain tumours, among other causes (Silva et al., 2019; Oliveira Martins Duarte et al., 2019). If detected in time, the prognosis of the PwD with a reversible dementia can result in eradicating or significantly delaying the underlying disease progression that may lead to an increased quality of life for the PwD (Day, 2020).

The following subsections cover three most common types of dementias found in the literature.

Alzheimer's Disease (AD). The most common type of dementia in the world is Alzheimer's Disease (Alzheimer's Society, 2017). In 1984, the National Institute of Neurological Disorders and Stroke-Alzheimer Disease and Related Disorders (NINCDS-ADRDA) formulated a well-defined guideline for the diagnosis of AD (McKhann et al., 1984). For over 27 years this report was considered as a reliable way to diagnose AD. However, in 2011 the NINCDS-ADRDA updated their diagnosis criteria to reflect the decades of scientific advances and to standardised their guidelines in such a way that not only

healthcare practitioners would be able to understand them, but also professionals from diverse disciplines (McKhann et al., 2011). Their updated diagnosis criteria for AD are divided into three types of classifications: “1) Probable AD, 2) Possible AD dementia, and 3) Probable or possible AD dementia with evidence of the AD pathophysiological process” (McKhann et al., 2011, p.265). The specific details of each category are beyond the scope of this thesis, nonetheless the details of each criterion can be consulted in (McKhann et al., 2011).

As a brief overview of this disease, AD is a damage in the functioning of the brain that causes a slow but continuous deterioration in the functions of memory, personality, and judgment, as well as the intellectual, physical, and emotional capacities of the person who suffers from it (Powell & Courtice, 2002). AD is a disease that is more likely to develop during old age (World Health Organization, 2012). Inside the brain “abnormal structures called ‘plaques’ and ‘tangles’ build up inside the brain. These disrupt how nerve cells work and communicate with each other, and eventually cause them to die” (Alzheimer’s Society, 2017, p. 16). In the early stages of AD, the person does not require constant care as they can continue living independently since they do not display any noticeable symptoms (Kumar et al., 2020). However, at the middle and later stages, they will eventually need physical, mental, and emotional support and will depend entirely on their family, medical, and social backgrounds (Knopman et al., 2019). The origin of Alzheimer’s disease is unknown and there is no accepted treatment to stop or reverse the disease process (Alzheimer’s Society, 2017).

Vascular Dementia (VaD). The second most common type of dementia is VaD (Alzheimer’s Society, 2017). The causes are unknown, although the risk factors are believed to be the same as those of heart disease: high blood pressure, high cholesterol diet, being overweight, smoking, and having a sedentary lifestyle (Kalaria et al., 2008). As in Alzheimer’s disease, there are no known cures that reverse the disease (Alzheimer’s Society, 2017). There is not a universal or defined set of pathological criteria to accurately diagnose this type of dementia since the two most reputable classification systems for VaD, the National Institute of Neurological Disorders and Stroke and the Association Internationale pour la Recherche et l’Enseignement en Neurosciences (NINDS-AIREN) and the Alzheimer’s Disease Diagnostic and Treatment Centers (ADTC) have different opinions and guidelines of what this type of dementia constitutes (O’Brien & Thomas, 2015). With that in mind, a narrow definition of VaD for the purpose of this thesis is “a progressive neurocognitive clinical syndrome that is caused by a decrease in cerebral blood flow and damage to the neurovascular unit” (Sinha et al., 2020, p.793). According to McAleese et al. (2016) VaD can be classified into three main categories, namely multi-infarct dementia, strategic infarct dementia or subcortical vascular encephalopathy. McAleese et al. specified that defining which subtype will be diagnosed is dependent on the distribution of the cerebral lesion in the patient. The clinical specifications, which are beyond the scope of this thesis, of each subtype can be consulted in (McAleese et al., 2016; O’Brien & Thomas, 2015).

VaD can be detected in various ways, such as using the Montreal cognitive assessment scale, the vascular dementia assessment scale (VADAS-cog), a pathological assessment of vascular lesions, cognitive decline, changes in behaviour and a post-mortem biochemistry assessment (Lees et al., 2014; Miners et al., 2016; Ylikoski et al., 2007). Some of the most common symptoms of VaD are changes in cognition and behaviour, such as executive dysfunction (i.e., cognitive, emotional, behavioural impairments) and psychomotor slowing (i.e., reduction of physical movements and emotional reactions), that are a result of the presence of subcortical vascular pathologies that interrupt areas of the brain that are responsible for information processing and attention (O'Brien & Thomas, 2015).

It has been speculated, that cholinesterase inhibitors such as galantamine could block the effects of acetylcholinesterase (i.e., a specific enzyme) (Kandiah et al., 2017; Shinagawa & Shigeta, 2014) . However, recent studies have suggested that these medicines make no significant change in the patients and should no longer be used and recommended as a course of treatment (Sinha et al., 2020). Another speculated treatment is using antihypertensives to prevent vascular dementia, instead of managing it (Peters et al., 2008). There are no Food and Drug Association (FDA) approved treatments for VaD (Alzheimer's Disease International, 2019). Furthermore, according to Iadecola (2013) , there are clinical trials that are "exploring other agents, including cholinergic stimulants (choline alphoscerate), vasodilators (udenafil), inhibitor of platelet aggregation (cilostazol) and delta-9-tetrahydrocannabinol" (p. 857).

Dementia with Lewy Bodies. According to Walker et al. (2015), there appears to be a conflation of the terms Lewy body dementias and dementia with Lewy bodies, as they are often used interchangeably within the literature. Although these concepts differ according to their clinical diagnosis (i.e., the timing of dementia in relation to parkinsonism), they both have similar underlying pathological changes. More specifically, these two concepts share a "deposition of α -synuclein in Lewy bodies and neurites and loss of tegmental dopamine cell populations and basal forebrain cholinergic populations, often with a variable degree of coexisting Alzheimer pathology" (Gomperts, 2016, p. 435). Lewy body dementias are the combination of dementia with Lewy bodies and Parkinson Disease dementia (McKeith, 2004).

In contrast, dementia with Lewy bodies is considered a type of dementia that is diagnosed before or simultaneously with parkinsonism, in the timeframe of one year of the decline of motor functions (Walker et al., 2015). The Alzheimer's Society (2017) defined it as a form of progressive dementia identified by "abnormal structures (Lewy bodies) forming inside brain cells" (p.3). It starts with a global deterioration or fluctuations of the main functions: memory, language, calculations, decision making, and visual space ability (Gomperts, 2016). Another symptom is the presence of visual hallucinations that are often complex, panoramic, full of colour and, in most cases, they occur upon

awakening (McKeith et al., 2004). It differs from Alzheimer's disease in its progress and effects and progresses faster in men than in women (Alzheimer's Society, 2017). Some indicators for a diagnosis of Lewy bodies may be frequent falls and a brief loss of consciousness (McKeith, 2002).

The common course of treatment for dementia with Lewy bodies is the management of specific symptoms (Gomperts, 2016). For example, acetylcholinesterase inhibitors and memantine are recommended for symptoms related to the patient's cognition and antipsychotic drugs such as clozapine, is used to reduce hallucinations (Walker et al., 2015).

1.2.2 Dementia in Mexico

Mexico is a country located on the northern subcontinent of America with a territory of approximately 1,943,950 square kilometres and an estimated population of 127,575,529 people (Worldometers, 2019). As of 2019, there is a 1.10% annual population growth (*ibid.*). Mexico's geographic location shares their northern border with the United States of America (USA), the Gulf of Mexico to their east, Guatemala and Belize at the south of their border and the Pacific Ocean to their west (Bernstein et al., 2019). It comprises a territory with a diverse geography that is divided by mountains, rainforests, and deserts (Kirkwood & Austad, 2000). This complex geography has affected contemporary Mexico in multiple ways. For example, Mexico's terrain has prevented the construction of an internal transportation system as the abundancy of steep valleys and mountainous land make transportation projects expensive and risky for construction workers (Bernstein et al., 2019). The frequency of earthquakes, volcanic activity, floods, and hurricanes makes people migrate from region to region, making some of the most stable regions overpopulated (*ibid.*).

In 2019, the 60 and older adult population in Mexico was estimated to be 9.4 million and it is projected to grow to 14.3 million by 2030 (UN, 2019). In 2015, 800,000 people were reported to be living with a type of dementia (Gutiérrez-Robledo & Arrieta-Cruz, 2015). It is predicted that by 2030, this number will increase to 1.5 million (Alzheimer's Disease International, 2016) and 3.5 million by 2050 (Sectretaria de Salud, 2017). Mexico is classified as a middle-income country with a GNI per capita of \$5,820 (The World Bank, 2020). Barry (2014) identified that there are approximately 401 licenced geriatricians in Mexico for the entire older adult population. He explained that this shortage is one of the reasons why family members are the main care providers in this country.

1.2.3 Mexican ICs of PwDs

There are two types of caregivers: formal and informal caregivers. Navaie-Waliser et al. (2002) defined formal caregivers as professional paid carers who, most of the time, are trained by a specific organisation. They usually have fixed daily hours with scheduled roles and tasks which, in many cases, need to be formally written or communicated to the patient's primary guardian. Conversely, Navaie-Waliser et al. (2002) described ICs as family members, very close friends, or even neighbours who care for the person. When relatives take on the caring responsibility, they either designate different roles or delegate complete control to one main person, who usually is a child or spouse of the PwD. Evidence suggests that there is a shortage of nursing homes for PwDs in LMICs; therefore, the role of informal caregiving is fundamental, since 95% of PwDs are cared for at home as opposed to in a nursing home (Alzheimer's Disease International, 2019). Women in LMICs tend to assume the role of ICs and dedicate an average of 49.96 hours a week to care-related activities (Wimo et al., 2018).

Becoming an IC of a PwD is a major life event and, in most cases, an unexpected and imposed role. Caring for someone with dementia is a challenging task because every PwD acts and reacts differently to treatments and environments (Brown et al., 2019). This new life-changing role places an immeasurable amount of stress on the family and the IC. The literature has clearly documented the different stressors that an IC faces as part of their caring role. These include the PwD's behavioural problems (de Vugt & Verhey, 2013), their limited ability to undertake activities of daily living (ADL) (Liu et al., 2007), fear of losing the PwD (for example, wandering) (Feast et al., 2016), dealing with the PwD's finances (Collins & Swartz, 2011), fear of developing dementia themselves, i.e.:the ICs (French et al., 2012), and feeling guilty (Oliveira et al., 2019).

There are few studies that provide information regarding Mexican ICs of PwD (Arevalo-Flechas, 2008). In research on Mexican ICs, there is a focus on comparison with other cultures (Adams et al., 2002; Knight et al., 2002; Stueve et al., 1997), the burden felt while caring for older adults (Prince et al., 2012; Ramírez et al., 2013), and depression (Covinsky et al., 2003; Islas Salas et al., 2006). There are difficulties in identifying characteristics from the literature, because, in existing studies, Mexicans are grouped with people from other Latin American countries (Sutter et al., 2016; Trapp et al., 2015) or are included as part of the Latino and Hispanic minorities from the USA (Coon et al., 2004; Gallagher-Thompson et al., 2003).

Domínguez-Sosa et al. (2008), Mendez-Luck et al. (2008), and De Valle-Alonso et al. (2015) generalised Mexican informal caregivers as females aged 18-50 who have completed tertiary education, are married, have a part-time job, and are one of the patient's children. Additionally, they commonly spend an average of 2.5 hours on ADL, that is, grooming, toileting, and dressing. They spend an average of 3.1 hours on 'instrumental activities of daily living' (IADL), for example,

transporting the patient and handling finances (Liu et al., 2013). In contrast, there are limited studies on male caregivers (Barry, 2014; Nance et al., 2018). Nance et al. (2018) highlighted that male Mexican informal caregivers are on average 50 years old, married, and Catholic. Currently, Mexican informal caregivers do not receive any type of income, preferential discount, benefits, or educational support from the government, making this a sacrificial job (Barry, 2014). Because of this, Mexican informal caregivers lack knowledge and training on how to manage PwDs (Alzheimer's Disease International, 2016). There is currently a reported shortage of approximately 819 nursing homes and 350 licenced geriatricians for a population of 12.4 million adults over the age of 60 in Mexico (Barry, 2014; Nance et al., 2016). Gutiérrez-Robledo & Arrieta-Cruz (2015) suggested that public medical and nursing homes in Mexico are poorly equipped for dementia patients.

Gutiérrez Robledo et al. (2012) explained that Mexican ICs can have access to health care for themselves, in three ways:

- a) insured through employment;
- b) uninsured but with access to public funds; or
- c) private sector with health insurance policies and private consultations.

From these options, only people who are insured through employment or are able to pay for private consultations can have access to support. The two main governmental institutions that provide healthcare for ICs are the *Instituto Mexicano del Seguro Social (IMSS)* which, translated into English, is 'Mexican Social Security Institute' and *Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (ISSSTE)*, or 'Institute for State Workers' in English. These two institutions can only provide their services to an employed IC or members from the nuclear family of someone who is employed, for example, the spouse (Government of México, 2020). These are described further below.

IMSS. IMSS is a governmental institution that offers health care to people who work in the private and public sector (Gutiérrez Robledo et al., 2012). This also applies to people who are self-employed or freelance workers (Mexican Social Security Institute, 2017). Through their official report "Detección y Manejo del Colapso del Cuidador" (Detection and Management of Caregiver Collapse), IMSS has made public the guidelines and procedures they follow when dealing with informal caregivers' physical and psychological medical needs (Mexican Social Security Institute, 2015). This document outlined that, by 2015, all medical personnel would receive formal training on how to manage informal caregivers' health from a psychological and/or physical perspective. The report describes in detail the different ways that doctors, psychologists, nurses, and social

workers can provide help through the institution. For instance, in the case of depression, doctors can prescribe antidepressants and should always encourage physical activity. Psychologists can offer individual or group psychotherapy where relaxation and coping techniques are taught. Nurses can only offer, through brochures, general information and examples of practical skills for caring for PwDs at home.

ISSSTE. This federal institution provides health care services only to people who work for the government in a federal or state office, and any member of their nuclear family (Gutiérrez Robledo et al., 2012). Currently, they only offer free training to ICs through a series of lectures delivered in different allocated facilities throughout the country. ISSSTE also offers an online course (Institute for State Workers, 2020) which is available to everyone through the ISSSTE official website (www.issste.gob.mx/cursocuidadores). The course offers theoretical and practical tools that cover how to care for a dependent family member at home from a physical, psychological, social, spiritual, and environmental perspective.

In Mexico, there are several non-governmental organisations that focus on different types of dementias. There is only one organisation that operates at a federal level called “Federación Mexicana de Alzheimer” (FEDEMA) which, translated into English, is the Mexican Federation of Alzheimer’s. FEDEMA works by supporting and collaborating with any registered organisation for patients with dementia throughout Mexico (FEDEMA, 2016). On their website, they state that one of their main objectives at a national level is to inform primary caregivers about dementia. The website accepts donations, which fund seminars, activities, support groups, their online forums, and individual therapy sessions, which continue helping burdened informal caregivers.

1.2.4 Mexico's particularities

Mexico was the first Spanish speaking country in the world to recognise dementia as a public health priority (Alzheimer’s Disease International & Bupa, 2013). In 2014, Mexico’s National Institutes of Geriatrics, Neurology and Psychiatry launched their National Dementia Plan called “Plan de Acción Alzheimer y otras Demencias”, which in English means ‘Alzheimer’s Disease and Related Dementias Plan’ (Snyder et al., 2016). In this plan, eight main strategies were proposed, with the main objective being to create awareness and to make dementia care and support available to Mexicans (National Institute of Geriatrics, 2014). In addition, the Federal Government of Mexico (2019) stated in their “National Plan of Development (2019-2024)” that they will invest in technology for health and education, as innovation in these areas is a priority to the nation.

In 2002, the Mexican government created a law called “Ley de los Derechos de las Personas Adultas Mayores”, which means ‘Law on the Rights of Older Adults’, which protects older adults against family neglect (Federal, 2002). This law forces citizens to provide necessary care needs,

e.g., food, housing and medicine, to frail, dependent, or disabled parents who are 60 years old or older. If citizens infringe this law, they could face prison (Federal, 2002). In Mexico, due to the scarcity of nursing homes, the aforementioned law, and the cultural stigma around them, ICs are forced to provide for their PwD (Nance et al., 2018).

Mexico is a diverse country with inherited cultural values that influence the caregiving experience (Baca Zinn & Pok, 2002; Mendez-Luck & Anthony, 2016). Values act as unwritten rules that influence the way people think, behave, and interact with the world (Arevalo-Flechas, 2008). Cauce & Domenech Rodríguez (2002) suggested that the following are core values that inform behaviour and are a representation of the Mexican culture: familismo (familism), machismo, mariianismo (marianism), and personalismo (personalism). Arévalo-Flechas et al. (2014) suggested that these values have a direct effect on how Mexicans perceive their caregiver experience. These are defined below.

Familism. Arévalo-Flechas et al. (2014) defined familism as that which “involves strong identification and attachment to the nuclear and extended family” (p.663). Families with this value are loyal and act in a reciprocal manner towards each other. This includes close friends and individuals who help raise their children, like nannies or maids (Guilamo-Ramos et al., 2007). Talamantes et al. (2006) suggested that Mexican families with a high sense of familism are more likely to accept their caring roles with a positive attitude. Hence, some studies report that Mexicans perceive less burden and feel accomplishment, stronger bonds, solidarity, and reciprocity when caring for older adults (Barry, 2014).

Machismo. Guilamo-Ramos et al. (2007) define machismo as “a constellation of attitudes and behaviours that accompany the leadership or decision-making role that men individually and collectively assume in the home and community” (p.19). Machismo can either have a positive or negative connotation in Mexican culture. It can be positive when alluding to manly qualities, where men are seen as providers, guardians, robust, and brave (Arevalo-Flechas, 2008). Yet, it can be negative when referring to men who are aggressive when confronted, arrogant, sexually belligerent towards women, and boastful about their virility (Gutmann, 2006). Arévalo-Flechas et al. (2014) explained that male caregivers who strongly identify with this value feel that asking for help is a sign of weakness, making their caregiving experience a burden.

Marianism. According to Cauce & Domenech Rodríguez (2002), the concept of marianism derives from Virgin Mary’s purity as portrayed in the Catholic teachings, in which femininity, caregiving, self-sacrifice, and suffering are emphasised as a woman’s ideal characteristics. Arévalo-Flechas et al. (2014) suggested that by emulating marianism, it “may lead caregivers to see their caregiving responsibilities as a fulfilment of their religious beliefs, God’s will, and a sacrifice to be

embraced” (p.665). Additionally, they identified that because of this social role, females are silent about the burden they experience whilst caring for a family member.

Personalism. Cauce & Domenech Rodríguez (2002) describe personalism as the importance that Mexicans “place on personal goodness and getting along with others, values considered more important than individual ability and material success” (p.12). Moreover, personalism is the creation of strong relationships and intimate friendships, mainly with those from the same ethnic group, by showing respect, loyalty, openness, and warmth (Arévalo-Flechas et al., 2014; Guilamo-Ramos et al., 2007). Arévalo-Flechas et al. (2014) reported that, due to personalism, Mexicans expect health and care providers to be empathetic and attentive. They highlighted that, in most cases, when Mexicans do not feel they can trust someone they will refuse or try to avoid any provided suggestions or available support.

1.2.5 Events that influenced contemporary Mexico

It is important to learn about certain events that shaped contemporary Mexico to understand some of the underpinning behaviours from the participants of this investigation. Three main events/occurrences will be described that range within their historical, political and societal context. The following subsections will provide contextual information that aims to aid the understanding of Mexicans and more importantly, to build up a coherent picture of the participants that will be discussed in Chapter 6.

Tlateloco's Massacre

In 1968, Mexico's President, Gustavo Diaz Ordaz, hosted the Olympic Games for the first and only time in Mexico's history (Carpenter, 2015). Prior to the event, media coverage was focused on how hosting the event was proof of Mexico's progression at an international level (Volpi, 1998). After all, this was going to be the first time in television history that the Olympic Games were going to be broadcasted live and in colour (Bustamante, 2013). President Diaz Ordaz allocated a large amount of money to fund the Olympic games. This annoyed Mexican citizens (Cornils, 2010). The government's investment had a massive negative impact on Mexico's economy that brought instability to the lower and middle classes (Carey, 2005).

In the same year, students and workers in France led a social revolution to protest against several governmental injustices and the views of the President at that time – Charles de Gaulle (Cornils, 2010). This particular social movement inspired Mexican students to start a series of protests demanding less expenditure for the Olympic games, better living and working conditions, and equality for citizens given that Mexico was ruled by an authoritarian and oppressive government

(Borden, 2005). The protests culminated with the Tlateloco's Massacre (Carey, 2005). This event happened just ten days before the 1968 Olympic Games began (Cornils, 2010). On October 2, 1968, the Mexican student movement was peacefully protesting in Plaza Tlatelolco in Mexico City when a group of armed forces fired blindly at them and any passing bystander as a means of intimidation and to forcefully end the movement (Borden, 2005).

The aftermath of the massacre led to 300 civilian deaths and around 1,200 injured, none of which was reported by the Mexican media (Poniatowska, 1975). This event marked what contemporary Mexico calls the 'day of resistance', when Mexican people started to demand change from their government and transparency from the media (Carey, 2005). The Tlateloco's massacre was only covered properly by the international press; in Mexico, it was reported that the students were the attackers and police retaliation was justified (Bustamante, 2013). This was a crucial moment for Mexicans because they realised that the government controlled the media and information could be distorted through technologies, which in this case were television and radio (Borden, 2005). Since the events of 1968, Mexicans have changed their opinions about the government as they grew in resentment and scepticism, which was reflected in numerous news articles, protests, vandalism, and riots (Poniatowska, 1975).

"Partido Revolucionario Institucional" (PRI)

To understand Mexico's political climate, it is important to explore pre-colonial Mexico. At this time in Mexico's history, the indigenous ideology dominated Mexico's cultural identity under the Aztec Empire (Hamel, 2008). The Aztec Empire was a highly advanced civilisation that created complex architecture (such as pyramids), had an educational system and medicinal and cosmological knowledge (Todorov, 1999).

Dunbar-Ortiz (2007) suggested that during pre-colonial Mexico, all different indigenous groups lived in delineated areas and respected one another's territory. However, everything changed after the 'discovery' of the New World with the Colonial period that lasted from 1519 to 1810 (Delgado & Gutiérrez Márquez, 2016). This is the period where Spanish conquistadores ruled the Aztec Empire for 500 years, imposing European philosophies, religion, and the Spanish language, and enslaving the indigenous people (Todorov, 1999). Trejo (2012) suggested this was a transitional period where Mexicans were forced to adopt the Spanish culture, whilst simultaneously fighting to keep their national indigenous identity. Thomas (2013) explained that rebellious slaves were starved, sold, or killed. It has been pointed out in the literature that the indigenous population declined and came under threat due to Spanish men who started intermixing with or marrying enslaved Mexican women (Ramírez, 2017). The children born from the union of people of indigenous and Spanish

descent were called mestizos (Hamel, 2008). Mestizos brought a new identity to Mexico which was an attempt at combining two different worldviews (Randall, 2006). Since mestizos were, at times, protected by their Spanish parent, most of them were raised with wealth and tended to be more Spanish-like, which made them blend with the Spanish community and elite (Van Young, 2001). Ramírez (2017) suggested that indigenous natives disliked mestizos because this group was privileged and considered superior by the Spanish conquistadores. This felt rejection on their own land made indigenous people experience a more intense desire for freedom (Todorov, 1999). Spain ruled for 500 years until Mexico's independence in 1810, led by mestizo Miguel Hidalgo who recruited and influenced indigenous people and mestizos to fight against the oppressive rule of Spain (Von Wobeser, 2011).

At the time of independence, Mexico was composed of 60% indigenous peoples, 22% mestizos, and 18% Spanish (Van Young, 2001). Expelling the Spanish conquistadores from their land was a moment in Mexico's history that defined Mexicans' sense of nationalism (Randall, 2006). After the fight for independence, indigenous people and mestizos attempted to find a new national identity for their re-gained nation given the many changes that had taken place, and because they wanted to protect and define the future nation's interests and political system (Hamel, 2008). Notwithstanding this, Mexico's indigenous and mestizos could not find a common ground to preserve each of their ethnic identities and languages (Van Young, 2001).

A century later, the clashing of mestizos and indigenous people, economic inequalities (indigenous people were poor and mestizos wealthy), and a governing dictatorship led to the events of the Mexican Revolution of 1910-1920 (Hart, 1997). The aftermath of this movement solidified the national identity of Mexico as mestizaje (pure mestizo) and their political climate was changed with the promulgation of a constitution (Sanjines, 2015). This view created a considerable amount of discrimination towards indigenous groups in Mexico (Randall, 2006). The end of the Mexican Revolution welcomed new political parties that helped shape what we now know as contemporary Mexico (Hart, 1997).

During the next elections after the revolution, the political party, "Partido Revolucionario Institucional" (PRI), which in English means "Institutional Revolutionary Party", created ties with several influential entities and criminal groups to gain power (Diaz, 2004). After winning, PRI provided protection and immunity to criminal groups, such as drug traffickers, to continue with their operations (Aitken et al., 2016). PRI ruled Mexico for 71 years and during that time, they monopolised and privatised state-run companies (which promoted nationalism), institutionalised the power of Mexican Revolutionary victors, and provided the Catholic Church with more power (and instilling Catholicism in Mexico) (Loaeza, 2013; Morris, 2009; Randall, 2006). The Catholic Church

at the time had the power to implement governmental decisions, could speak about their political views at liturgical services, and actively participate in public debates (Loaeza, 2013). During this period, Mexicans saw much injustice, corruption, and violence, which changed the citizens' mentality about their government (Morris, 2009). Thus, this political party (PRI) used their values to shape and define contemporary Mexico's political climate (Aitken et al., 2016).

Gender inequality and traditional gender roles

In Mexico, the identified traditional female roles were motherhood, caregiving, and educating the family (DiGirolamo & Salgado de Snyder, 2008). Díaz-Loving et al. (2011) explained that in Mexico, all traditional female roles are rooted in the value of marianism (as described in section 1.2.4). Proponents of this ideology try to educate women so that they mimic and aspire to the ideal of the 'perfect woman' as portrayed by the Catholic Church, namely, the ideal of the Virgin Mary (Cauce & Domenech Rodríguez, 2002). The expected behaviours within marianism are dependence on men, submissiveness, a positive attitude about motherhood and childbearing, passivity, and self-sacrifice (DiGirolamo & Salgado de Snyder, 2008).

Several authors have suggested that gender inequality is still an issue for Mexican women since Mexico is a patriarchal nation (DiGirolamo & Salgado de Snyder, 2008; Englander et al., 2012; Ramírez López et al., 2019). Arceo-Gómez (2016) published figures that sustain the aforementioned argument. For example, the female labour (41%) participation rate is substantially lower than for males (73%) and the female employment rate is 40% versus the male employment rate of 70%. She explained that this phenomenon exists because Mexican females are raised to aspire to and embrace their biological role of childbearing and caregiving. A further discussion of this value will be had in section 6.3.1

1.2.6 Assistive Technologies (ATs)

In dementia research, ATs (for which a detailed description is provided in section 2.4) is the general term given to any item or equipment that reduces the patient's dependence on informal caregivers by assisting them with the effects of dementia (Assistive Technology Industry Association, 2016; Bryant & Bryant, 2003). Peterson et al. (2012) suggested that ATs have the potential to increase the patient's and the caregiver's quality of life. They outlined that this occurs when the purpose of ATs is to help patients remember or retain information, and allows them to make decisions and carry out ADL unassisted. Furthermore, Bryant & Bryant (2003) classified ATs as low-tech and high-tech interventions. They emphasised that low-tech devices are non-electronic aids such as a cane for walking, whilst high- tech devices are automated and/or computerised, like hearing aids.

In 2014, the World Health Organization (WHO) established “the Global Cooperation on Assistive Technology” (GATE) that aimed to expand global access to ATs, which will ensure that anyone with a disability could have access to affordable and high-quality ATs (Tebbutt et al., 2016). In 2015, the WHO claimed in their “Global Disability Action Plan 2014-2021” that only 10% of the global population has access to an AT even though they stated it to be a human right (Boot et al., 2017). According to Asghar (2018), the top 10 countries leading the research field of ATs in dementia care are the USA, the United Kingdom, Canada, Sweden, Italy, Germany, Netherlands, France, Australia, and Spain. An important point to be raised is that all these nations are considered to be high-income countries in the Western world (apart from Australia). Only few studies have reported how and which types of ATs for dementia care are being used and developed in LMICs (i.e., Pryor et al., 2018; Asghar, 2018; Kasliwal & Patil, 2017; Palacios-Navarro et al, 2015; Navarro et al, 2016). This should be of great concern to healthcare and policy makers since it has been stated that as of 2018, 60% of PwD were reported to reside in a LMICs and it is expected that by 2040 this figure will increase to 71% (The World Health Organization, 2018). In addition, the WHO (2014) reported that only 5% to 15% of people from LMICs have access to ATs. This imminent demographic shift in dementia cases will affect LMICs as their depleted health infrastructures and lack of governmental support will be unable to meet the demand for essential support and care (Prince et al., 2015). It is therefore evident that the future rise in global dementia cases will have a greater impact in LMICs compared to HICs.

It can therefore, be argued that, since the state of the art of ATs in dementia research concentrates in HICs, then the design and development of ATs solutions in LMICs, in essence, is based on the ideas of countries that have different cultural, political and social infrastructures (Matter et al., 2017). There are a few studies on technologies for PwDs in Mexico (e.g., Beltrán et al., 2014; Diaz-Ramirez et al., 2013). However, there are no studies about the experiences of Mexican ICs of PwDs (or any Latin American country) using ATs at home. It is therefore clear that research is needed to inform and create better solutions for ICs and their PwDs in Mexico and similar cultures.

1.3 Statement of Problem

Currently, the number of studies investigating the perspectives of PwDs using ATs is vast. In the particular case of ICs using ATs, several studies suggest a focus in understanding ICs experiences after a technology has been adopted and/or used (Dadlani et al., 2010; Fuentes et al., 2013; Ehleringer and Kim, 2013). It is important to note that in most of these cases, the documented technologies are not necessarily an AT and/or intended to be used to support the daily activities of a carer. Furthermore, the literature suggests there is an interest in developing technological solutions to alleviate the stress and overall emotional wellbeing of the ICs (Ehleringer and Kim, 2013; Fuentes et al., 2013). There are also studies reporting technological solutions to alleviate the caregiver's burden that develops when

a carer cannot find activities or ways to keep their PwD entertained (Green et al., 2012; Gerling et al., 2014; Navarro and Favela, 2011). However, it appears that there is a clear gap about ICs experiences specifically with ATs to support their caring role in a LMICs. When ICs use the ATs for the purpose of their caring role (for example, monitoring a PwD), the technology becomes a mediator of the caregiving experience. Before the AT, the caregiving experience only involved the IC and the PwD since the interaction was one-to-one (that is, a direct experience). After the adoption of the AT, it is involved in the role and therefore, the experience is transformed into something substantively different. The experience of the IC will now be influenced by the AT since the technology now mediates the caregiving experience. There are few studies that explore experiences mediated by technology (Ihde, 2009; Kiran, 2015; Rosenberger and Verbeek, 2015; Verbeek, 2005). However, there are no studies in which the experiences of ICs using ATs for their caring role in a LMIC are investigated (discussed further in section 2.5.2). The study in this thesis is interested in the intersection of ATs and the caregiving experience, therefore, understanding the meanings that ICs place on the caregiver experience while using the AT could potentially develop new knowledge about the way that technologies shape, in this case, not only the IC, but also the caregiver experience. Schraube (2013) suggested that a way to understand the complexities of human-technology interactions is through subjective experiences. He suggested focusing on human subjectivity within a particular context allows the researcher to examine the nature and significance of technology in a particular experience. Moreover, he suggested that concentrating on a first-person perspective provides an in-depth account of the feelings, thoughts, actions, and sense-making of a complex experience. Thus, this study focuses on exploring the lived experiences of Mexican ICs of PwDs with ATs.

1.4 Research Question

In consideration of the defined problem statement from the previous section, the following research question was grounded in the epistemological position of interpretivism. Its focus is on exploring the experiential connection Mexican ICs of PwD develop with ATs and how they make sense (described in section 2.5.1) of ATs mediating their experience.

How do Mexican informal caregivers of people with dementia make sense and experience their use of assistive technologies to aid their role?

1.5 Research aim and objectives

The overall aim of this research is to examine in detail the experiences of Mexican ICs of PwD who use ATs for their caring responsibilities. This study explores the role and impact of ATs in the caregiving role and caregiving experience. This means that the subjective experiences of Mexican ICs of PwD interactions with the ATs that supported their role will be elicited. Eliciting the feelings, thoughts, and beliefs of the ICs will provide an insight into the social and cultural complexities of the caregiving experience. Additionally, it will delineate the meanings that ICs give the ATs and the caregiving experience. More specifically, the following are the objectives of this project:

- To explore what drives Mexican ICs to use ATs as a support in their caring role.
- To identify what types of ATs that are being used by the participants of this study.
- To understand for what purpose Mexican ICs use the ATs for their role.
- To determine what influences the perspective of Mexican ICs of PwD during their caregiver experience with ATs.
- To identify in what way does the ATs influence the ICs' role and caregiver experience.

1.6 Thesis outline

This thesis is divided into seven chapters.

Chapter 1 is a comprehensive introduction to the study. Firstly, there has been a presentation of existing data on dementia and LMICs as part of the background of the research. This was followed by an introduction to the different elements that comprise the context of this research. The next section defined the problem statement which outlined the general and specific issues that the study will address. Finally, there was an introduction to the research aim and objectives.

Chapter 2 consists of the literature review that identified the gaps addressed in this research. The first section describes the search strategy that was divided in two phases. It followed with an overview of ICs of a PwD. The review starts with an exploration of the different challenges an IC faces as part of the caregiving experience. There is also an exploration of the different types of caregiver burden and existing support interventions for ICs of PwD. It continues with an introduction to the different areas of interest within the literature of ICs of PwDs, specifically in LMICs. Within the second section, there is an exploration of the literature of ATs and dementia care. It starts by explaining what an AT is and the different applications that it has in dementia care. The following discussion is of the identified categorisations of ATs within dementia care and with a conclusion emphasising the importance of ethical considerations when designing ATs. The third section presents the relevant research on ATs for dementia care in LMICs. It commences with a presentation of the different research strategies that have been used by studies that evaluate experiences with ATs in dementia care. Previous studies on ATs for dementia care in LMICs are discussed and finally, there is a consideration of future developments for technology in dementia care. The last sections provided a synthesis of the literature review and the identified gaps within the literature.

In *Chapter 3*, an extensive explanation and justification of the selected methods for this investigation are provided. The chapter starts by exploring the different elements that constitute the research philosophy of the research and it defines the researcher's philosophical stance. There is also a detailed description of the selected methodology for this research, i.e., Interpretative Phenomenological Analysis (IPA), and a discussion of the alternative approaches that were considered. The discussion continues with the steps for conducting IPA, its limitations, and the procedures that were followed for assessing the validity and credibility of the research. The chapter concludes with a description of the importance of reflexivity and a reflexive statement from the researcher.

Chapter 4 consists of the results of the idiographic analysis. The chapter starts with the details of how the analysis was conducted. This is followed by an introduction of the results of the analysis in the form of in-depth interpretative accounts for each participant. After each account, a reflexive box has been placed to acknowledge the positionality of the researcher.

Chapter 5 comprises the results from the group analysis. The first section details the procedure followed for the group analysis. There is then a discussion of the results of the group analysis, highlighting the convergences and divergences among them. The chapter closes with a synthesis of the findings and a reflexivity statement from the researcher.

Chapter 6 contains a discussion of the findings of the present study. The chapter starts with an in-depth, critical discussion of the historical, social, and political factors that formed the participants' worldview. A comprehensive discussion of the findings in relation to the identified patterns from the group analysis is presented using a diagram. There is also an exploration of how the ATs acted as mediators during the last stage of the experience using concepts from postphenomenology. Finally, the chapter concludes with a summary of the discussion.

Chapter 7 concludes the thesis with the provision of a summary that details the way the research question and objectives were addressed in this investigation. It also outlines the contributions to the existing knowledge as well as the limitations of the research. The chapter closes with individual recommendations to different stakeholders and suggestions for future research.

1.7 Conclusion

This chapter has provided an introduction to the thesis and the study that was undertaken. It provided background information to the main elements of this study, namely dementia, Mexico, ICs and ATs. It presented the over-arching research question as well as the aim and objectives of the study. The structure of the thesis was described. Having introduced the thesis, the following chapter presents the literature review that was undertaken for the study.

Chapter 2: Literature review

2.1 Introduction

Chapter 1 of this study presented a comprehensive introduction for this investigation and the structure of this thesis. This second chapter, presents the literature review of this investigation and identifies the gaps found in the literature. The review focuses in three main areas: informal caregivers (ICs), assistive technologies (ATs) and dementia care research with ATs. In section 2.3, a holistic picture of the fundamental role of ICs in the fight against dementia is discussed. There is a specific focus in understanding the challenges that ICs endure after the diagnosis of dementia. Within these challenges, the concept of caregiver burden will be explored and the support interventions that have been used in previous studies to alleviate the many challenges of the caregiver experience. Section 2.4 presents the different types and elements of interest around the literature of ATs for ICs of a person with dementia (PwD). For example, the various applications and categorisations that have been allocated to ATs. This section also explores the different ethical considerations when designing ATs for dementia care and how these could affect the different stakeholders of the caregiver experience. Finally, section 2.5 examines the state of the art in research on ATs for PwD. The current literature focuses on exploratory studies that evaluate the lived experiences of ICs from low- and middle-income countries (LMICs).

2.2 Literature Review Methods

The literature search for this report was divided in two phases. The first phase consisted of a literature review that was developed for the researcher's first year report as part of the departmental requirements to progress from Doctorate Candidate to Doctorate Student. In 2016, the researcher developed a comprehensive research proposal that included among its main components the aforementioned literature review that identified the gaps within the literature and a methodology chapter to review the different methods used in the social sciences to select an appropriate one for the investigation. This report aimed to inform the researcher of previous work and relevant concepts from the area of interest, namely ATs for ICs of PwD from a developing country. The report concluded that, given the epistemological nature of the research question and aim of the investigation, as presented in Section 1.4 and 1.5, an inductive qualitative study using a phenomenological approach would be the most appropriate approach (see Section 3.3.1 and 3.3.2).

Several authors have suggested that, when conducting an experiential study, the literature review should be developed *after* the data collection and analysis stages (Flowers et al., 2001; Larkin et al., 2019; Smith et al., 2009). This point of view argues that by writing the literature review after data collection, the researcher will be less likely to influence the way that participants' express their experiences as he/she will not be biased by what was found in the literature. Notwithstanding this, the opposing view suggests that a researcher needs to conduct an initial literature review *before* the data collection and analysis to inform them about the gaps in research, formulate a research question and identify the leading authors from the desired area or research (Smith et al., 2009). In both cases, researchers are required to demonstrate validity through the process of 'bracketing' (Chan et al., 2013). In phenomenological studies, bracketing refers to the method in which a researcher consciously suspends any previous knowledge, prejudices and biases of the subject under study to avoid tainting the results (Gearing, 2004). There is a lack of consensus about the best way to achieve bracketing (Beech, 1999; Glaser, 1992). However, Chan et al. (2013) suggested that exercising reflexivity (see Section 3.5) is considered a good way to demonstrate bracketing.

As previously mentioned, the researcher conducted a literature review prior to the process of data collection and analysis. The main databases searched for the first phase (i.e., evaluative literature review) were PubMed, ACM digital library, ProQuest, Web of Science, Elsevier- Science Direct , IEEE online xplorer, Scopus and Medline. Studies in the English and Spanish language were included. Key terms included: 'informal caregivers dementia', 'informal caregivers home care', 'informal caregivers technologies', 'informal caregivers Alzheimer's Disease', 'informal caregivers perceptions', 'informal caregivers lived experiences', 'technologies dementia'. The exclusion criteria at this initial stage consisted in discarding implantable technology and studies that focused on nursing homes.

The second phase consisted of a thorough literature search that was developed between 2017 to 2020, to update the initial literature search and review. The same databases from the first phase were utilised and theses from ProQuest, White Rose eTheses Online, eTHos and Dart Europe E-theses Portal were incorporated into the search strategy. The following key terms were browsed in English and Spanish: 'family caregivers dementia', 'informal caregivers dementia', 'informal caregivers IPA', 'informal caregivers assistive technologies', 'informal caregivers lived experiences', 'assistive technologies lived experiences', 'informal caregivers developing countries', 'informal caregivers Mexico', 'informal caregivers latino'. Studies using qualitative, quantitative and mixed-methods were considered. Studies excluded were those that involved formal caregivers, caregivers of older adults in a nursing home, informal caregivers of patients with other diseases, i.e., different to dementia and healthcare professionals (e.g., medical

doctors). The literature revealed that the subject of technologies for informal caregivers of a person with dementia was mostly in English. Therefore, SciELO and ResearchGate, were included to the repertoire to increase the number of articles in Spanish (the researcher's first language).

2.3 The Informal Caregivers of People with Dementia

This section of the review, focuses on providing an overview of the experience of being the primary caregiver of a family member with dementia at home. Having an understanding of what the literature reports about the ICs, informs this investigation about the impact that the role of caregiving on the person who assumes it and the gaps that need to be addressed. The discussion concentrates on four main areas: Section 2.3.1 describes the fundamental role that ICs have in dementia care. Section 2.3.2 introduces the different challenges that ICs face after learning and acknowledging a family member is diagnosed with dementia, Section 2.3.3 explores the concept of caregiving burden and its contributing factors, Section 2.3.4 introduces the different support interventions for ICs of PwD and finally, Section 2.3.5 provides an exploration of previous studies of ICs of PwD in LMICs.

2.3.1 The importance of ICs in dementia care

The World Health Organization (2018) reported that, worldwide in 2018, an estimated 50 million people were diagnosed with a type of dementia. As of 2019, the estimated annual cost of dementia was of \$1 trillion and it is expected that, by 2050, this figure will double (Alzheimer's Disease International, 2019). The professional care sector is unprepared for the increasing cases of dementia around the world (Zwaanswijk et al., 2013). This reality is making governments and healthcare professionals rely on informal care to rise above this imminent outcome (Vandepitte et al., 2016). Informal caregivers are an unrecognised and unpaid group of people that sacrifice their own physical, financial and psychosocial wellbeing to provide care for their loved ones (Embracing Carers, 2017). Reports suggest that worldwide ICs of PwD have unmet needs and in low- and middle-income countries (LMICs), the inadequate support brings numerous challenges into their caregiving experience (World Health Organization, 2017). Giesbrecht et al. (2012) suggested that in the past, informal caregiving was treated as a private and discreet family matter. Currently, ICs have slowly become the backbone of health and social systems all over the world with their unrecognised work. Therefore, it is in healthcare and social systems best interests to understand the experience of being an IC since it is a role full of nuances. This section concentrates on emphasising how varied and complex responsibilities for ICs can be. It also aims to describe how ICs influence the life of PwD and the way that culture affects the ICs experience.

The many responsibilities of an IC

Dementia is a complex disease that affects each person differently, making it unpredictable and difficult to manage (Brown et al., 2019). Ponnala et al. (2020) suggested that most PwD are cared at home by an IC who is usually helped by a support network (e.g., family and friends) that provides care for the PwD within a familiar surrounding for comfort and to delay institutionalisation. They also stated that, in many cases, ICs improvise day by day with the limited resources that they have. Evidence suggests that ICs of PwD are considered a vulnerable group since they are more likely to develop depressive disorders and higher levels of caregiver burden (described in section 2.3.3) than other types of caregivers, in response to the accumulation of stressors that ICs are subjected to as part of their many responsibilities (Bertrand et al., 2006; Cuijpers, 2005). The World Health Organization (2012) stated that some of these stressors can include: financial problems, the ICs own mental health issues, the relationship between IC and PwD, activities of daily life (described in section 2.4.2), managing the PwD's behaviours (described in section 2.3.2), progressively making all the decisions for the PwD and keeping the PwD safe.

Sanders and Power (2009) conducted a study with 17 male carer spouses of PwDs (all female) to investigate what their responsibilities as primary caregivers were and how the role had affected their marriages. The results from that study stated that male carer spouses' responsibilities were to protect the self-esteem, dignity, and personhood of their spouse, provide companionship and daily care, plan their spouse's life (such as social activities), and housekeeping. The multidimensional role brought strains into all the marriages since the spouses had to accept the finality of their romantic relationship and adapt to the changes that dementia brought into their lives. Participants also felt that caring for their wife was something expected and a normal part of marriage. Similarly, Egdell (2013) explored the evolving responsibilities of ICs of PwDs and her results echoed Sanders and Power's stated responsibilities, however, she also included adult child carers in her study. The results from their interviews contrasted with the views from spouse carers in both of the aforementioned studies. Egdell reported that the responsibilities of an adult child carer were activities of daily life, transportation of their parent with dementia, provision of food and healthcare, and in some cases, formal support to balance their responsibilities with their own children and spouse. Notwithstanding this, Egdell (2013) explained that adult child carers, unlike spouse carers, go through a complex process of internally negotiating the boundaries of their caregiving role. She suggested that these are influenced by their social, cultural, moral, emotional and spatial rationalities that adult child carers have at the time they become primary caregivers.

These two contrasting views demonstrated the range of responsibilities and demands that the role of informal caregiver can entail. Researchers of the previous studies presented the perspective of a specific group of ICs that could not be generalised to an entire population. However, the aim of the examples was to demonstrate that informal caregiving is multidimensional and complex because care is different when provided by a spouse to when it is provided by an adult child. In the case of a spouse, there is the willingness to support and protect the emotional and social dimensions of the PwD, whilst the adult child appears to be committed in the provision of healthcare and the fulfilment of basic human needs (for example, food). Both perspectives have a degree of complexity since the quality of the care appears to be proportional to the nature of the relationship with the PwD. Thus, the spouse carer is more likely to view the responsibilities as part of their marriage and the adult child carer as a way to provide the same care they received when they were a child.

The integral role of IC in the PwD's life

In 2015, the annual value of unpaid work provided by informal carers to PwD was evaluated at \$818 billion – nearly 1.1% of the global GDP (World Health Organization, 2017). These numbers, as well as future projections, demonstrate how ICs have progressively become the backbone that invisibly aids healthcare and social systems (Giesbrecht et al., 2012). Ponnala et al. (2020) suggested that gerontologists acknowledge the integral role of ICs in dementia care since they are the only ones who have daily contact and a deep understanding of the PwD's life. In addition, they explained that ICs could be the only stakeholders who can provide key insights into the real factors that affect the progression of the illness and the PwD's reaction to certain treatments. However, extracting this tacit knowledge is complex since PwDs have evolving and unique needs that require a person-centred care (namely, tailored treatments), making it difficult to develop generic solutions (Brown et al., 2019). Tang et al. (2018) implied that ICs not only provide dementia-related care but are also “responsible for gluing all the different parts of caregiving together” since they act as representatives who communicate information about the wellbeing (for example, changes, treatments, progression) of the PwD to doctors, family members, and interested parties (p. 79). Similarly, Hahn-Goldberg et al. (2018) suggested that ICs also function as supervisors and advocates of the PwD since they are cognitively impaired and feel the need to protect them. They explained how ICs are more likely to go beyond the care and needs that a formal caregiver would give a PwD since ICs feel a responsibility that stems from a previously formed relationship (for example, a family relationship).

Another invisible activity from ICs is that they manage all the pre-existing medical conditions that the PwDs have and will develop as they age such as diabetes, life-threatening allergies, and dental problems (Bratteteig and Wagner, 2013). Taking this into account, most ICs have no training or previous experience in caring for a PwD, making taking on health-related responsibilities an overwhelming experience (Tang et al., 2018). Moreover, Gräsel (2002) suggested that another general misconception about ICs is that their care ends when the PwD is admitted into a nursing home. He explained that this is not the case, since the ICs have to be in constant communication with health professionals and formal caregivers from the nursing home, providing information about the PwD, responding to emergencies, and paying for fees, medications, and supplies (such as incontinence pads). However, Wang et al. (2013) reported that there is a shortage of nursing homes and a lack of governmental support in LMIC that forces family members to care for PwDs at home. Accordingly, it can be argued that studying the experiences of ICs is an essential part of understanding the complexities that carers in LMIC endure.

In 2017, the World Health Organization (2017) reported that in LMIC, hundreds of people affected with a type of dementia were not diagnosed, treated, or cared for. They explained that this situation stems from the misconceptions, stigmas, and religious beliefs that certain LMIC have (see section 2.3.5 for more details). Therefore, it is imperative that attention is placed at increasing dementia awareness in LMIC. This will allow PwDs to get appropriate care and increase their quality of life (Fletcher, 2020). It could also inform families about the available support interventions that could equip them to make informed decisions and acquire skills for a future caring role. From this perspective, it can be argued that ICs are an integral part of the current state and future improvements for the provision of dementia care in LMIC. Thus, the value that each individual IC has can no longer be denied and unrecognised since governments and healthcare systems will become increasingly dependent on them to address future cases of dementia.

The impact that culture has on ICs

The literature about the influence of culture in dementia care is divided. For instance, there are authors that suggest that culture shapes the caregiving experience (Aranda and Knight, 1997; Knight and Sayegh, 2010). To understand this argument better, in this review, the concept of culture will be referred to as “the collective programming of the mind which distinguishes the members of one group or category of people from another”. (Hofstede et al., 1991, p.5). Therefore, stating that culture influences the caregiving experience implies that by studying the social interactions and groups of ICs, the necessary information would be provided to create appropriate

interventions since culture is a socially constructed concept. If this argument is true, then by implication, researchers should consider ICs' ethnic backgrounds because ethnicity (shared ancestry, cultural identity, and traditions [Merriam-Webster, 2020b]) influences cultural behaviours (Aranda & Knight, 1997). To apply the idea of culture shaping the caregiving experience to the specific context of Mexico, would mean that knowledge of Mexican traditions, values, national pride, cultural traits, and social behaviours should be enough to create better policies for all ICs residing in the country.

Furthermore, there is also the belief that the meaning a culture ascribes to dementia determines the way an IC provides care and seeks support (Dilworth-Anderson & Gibson, 2002). It has been argued that when ICs of a particular cultural context create a negative belief around the concept of dementia, the collective misconception prevents and/or delays people from getting diagnosed with a type of dementia (World Health Organization, 2017). Fletcher (2020) suggested that this situation is prevalent in LMIC and that it typically affects minority ethnic groups. He states that the existent literature of the awareness that minority ethnic groups have about dementia comes only from HICs. Therefore, he argues that researchers should focus on understanding the meanings ethnic minorities place on dementia to develop better interventions for ICs from those groups.

Several authors have implied that ICs are influenced by the cultural expectations that their family members colloquially or traditionally establish (Scharlach et al., 2006; Napoles et al., 2010; Montgomery, 2014). This statement suggests that investigating family-driven values from specific cultural contexts could provide an insight into the factors that motivate and impact the experiences of ICs. McCleary and Blain (2013) stated that the two main family-driven values within the literature are filial piety (honouring parents with gratitude and reciprocity [*ibid.*]) and familism (described in section 1.2.4). They also highlighted how familism is typically practised in Latin American countries and filial piety in Asian cultures. Yiu et al. (2020) conducted a study with Chinese ICs of PwDs that explored the influence of filial piety on their caregiving experience. Their results hinted that ICs with a higher affinity with this value sought formal support services, felt motivated in their provision of care, and reported lower levels of burden. In their discussion, it was acknowledged that their results were significantly different to other Chinese studies (Xiao et al., 2014; Dai et al., 2015). A potential explanation for this outcome might be that Yiu et al.'s study was conducted in Hong Kong, whilst the other two were carried out in mainland China. There is substantial evidence that there are cultural differences between these two locations and that this may account for the different outcomes (Dong & Xu, 2016).

There is considerable literature exploring the value of familism in Latino groups. Notwithstanding this, results about familism in Latino communities are not applicable for every Latin American country. There is a clear difference between Latino and Latin American communities. Latino is a term used in the United States that refers to American citizens that were either born in or have a direct background from a Latin American country (Aranda & Knight, 1997). Therefore, all studies reporting the influence of familism cannot be generalised to Latin American countries, but only used for comparison. Studies conducted in Latino communities report conflicting results. For instance, Mendez-Luck et al. (2016) showed that familism affected the ICs negatively, suggesting increased levels of burden that resulted from the sense of familial obligations that ICs felt. Another study reported that ICs of PwDs believed familism had no influence in their experiences since the participants argued that the younger generations of Latinos disavowed this value (Gelman, 2014).

Moreover, only two studies have been identified that measured the influence of familism in ICs of PwDs from a Latin American country. In Santos et al.'s (2013) work, ICs from Brazil were interviewed to understand the reasons why they chose to be the primary caregiver of their PwD. Findings suggested that familism influenced their experience in a positive way since participants felt content with their role (even when the relationship was unhealthy before the diagnosis) and displayed positive coping skills. The second study was conducted in Mexico but with ICs of people with Parkinson's disease. Trapp et al. (2019) examined the influence of the families of ICs in their role and the effects that it had on their perception of burden. The findings from this study echoed those of Santos et al.'s study in that familism had a positive impact in their lives and on their experiences. Mexican ICs that described having a healthy relationship with the person with Parkinson's resulted in lower levels of burden. Although the aims of both studies were different, the results were very similar suggesting that cultural expectations in Latin America positively influence the caregiving experience in comparison to Latino communities in the USA. Therefore, it can be argued that since familism in Latin American countries creates a positive impact, other known values (for example, marianism and machismo [see section 1.2.4]) should be further explored to examine their influence in the ICs' experiences.

Finally, it can be concluded that culture influences the ICs' views and experiences in various ways. This section stated that, to a certain extent, culture shapes the caregiving experience. This means that in order to make appropriate interventions, special attention should be given to the carers' ethnic background since ethnicity influences culture and not the other way around. This approach would then allow researchers to formulate and explore the nuances that exist between ethnic minorities to create better interventions. In this review, it was also discussed how the meaning that cultures attribute to dementia has an enormous impact on an ICs' provision of care since misconceptions create cultural stigma. Moreover, it was shown that cultural expectations influence

ICs' motivations for care and perception of burden. Specifically, it was stated that filial piety and familism are the two most prominent family-driven values within the literature. The focus of the next section is one of the many challenges that ICs have to overcome during their caring experience.

2.3.2 The challenges of dementia caregiving at home

There is a clear consensus that dementia care can bring considerable challenges to family caregivers (de Zwart et al., 2017; Chiao et al., 2015). Three main challenges were identified within the literature of informal caregivers of PwDs: ICs adapting their home for the new needs of the PwD (Soilemezi et al., 2019), learning to understand and manage the PwD's symptoms (Feast et al., 2016), and processing the ICs' ambivalent feelings throughout the experience (Losada et al., 2016). Understanding the impact that each of these challenges have on the caregiving experience sheds light on the different ways it affects ICs' quality of life.

Home adaptations and domestic environment

When a family decides to care for a PwD at home, modifications are required to keep the place familiar and safe for the patient. The information required for these modifications is found on websites, leaflets, advice from non-profit associations, and specialised literature. The Alzheimer's Society (2015) suggests that if modifications feel restrictive, patients will be less active, reducing their cognitive functions and increasing the progression of dementia. Literature for the appropriate ways a family can adapt their home for an older adult with dementia is limited. Hadjri et al. (2015) suggested that a reason for this is because most ICs from developed countries, out of necessity, have to send their PwD to specialised nursing homes that will provide the appropriate safe and caring environment for residents. However, this is not the case for people living in LMIC. According to Guerchet et al. (2018), in LMIC one has to consider that cultural values, the country's healthcare system, and the lack of support interventions play a fundamental role in the ICs' decision to care for their PwD at home. They explained that because of these factors, there needs to be a focus on how to inform people from LMIC to appropriately care for their PwD at home. After all, evidence suggests that a PwD's physical environment affects the progression of dementia (Van Hoof and Kort, 2009).

Marquardt et al. (2011) suggested that there are two main areas in home modifications for PwDs: *physical limitations* and *cognitive deficits*. Most caregivers focus on physical limitations, forgetting the importance of cognitive deficits. The literature shows that there is resistance from the ICs on the cognitive side regarding home adaptations. Aminzadeh et al. (2010) suggested that ICs tend to avoid cognitive aids since the adaptations could disrupt the feeling of homeliness for the PwD. The most common cited adjustments included placing signs and labels around the house as reminders and wayfinding cues with vivid colours (Marquardt et al., 2011). De la Cuesta (2005) explained that

ICs avoided this type of adaptation because some changes could make other family members and visitors uncomfortable since the house environment revolves around the safety of the PwD (for example, unpleasant smells, locking doors with keys, and surveillance equipment). Furthermore, when talking about the possible modifications to aid physical limitations, several authors (Brawley, 2001; Marquardt et al., 2011; Lawton, 2001; Cohen & Weisman, 1991) and the Alzheimer's Society (2015) explained that the most common changes carried out in a home environment with a PwD were implementing bright contrasting lights, non-slip flooring, handrails for staircases, and toilet safety rails. In a similar vein, there are families that preferred downsizing or limiting the PwD's space to reduce the cost of home adaptations (Aminzadeh et al., 2010; Olsen et al., 1996). In short, the purpose of adaptations that aid physical limitations should be to provide a safe environment in a familiar space (De la Cuesta, 2005).

Managing Behavioural and Psychological Symptoms of Dementia

Behavioural and psychological symptoms of dementia (BPSD) are generally defined as the variety of different psychological and/or psychiatric behaviours that PwDs display as part of their dementia symptoms (Finkel & Burns, 2000). Examples of BPSD are paranoia, hallucinations, apathy, agitation, depression, aggression, inappropriate sexual conduct, wandering, and anxiety (Onishi et al., 2005; Fauth & Gibbons, 2014; Feast et al., 2016). The caregivers' literature on BPSD focuses on the challenging circumstances that derive from the dynamic behaviour of PwDs and how these affect the quality of life and stress levels of ICs (Moniz Cook et al., 2012; Fauth & Gibbons, 2014; Nogales-González et al., 2015). Finkel (2004) suggested that this focus exists because PwDs with BPSD symptoms are more likely to experience a deterioration in their cognitive and functional abilities faster than those who do not experience them. By addressing these symptoms correctly with the appropriate interventions, both the caregivers' and patients' lives may be highly improved and institutionalisation may be delayed (Raglio et al., 2015; Almeida, 2019).

There is no clear understanding as to why BPSD symptoms appear at certain stages of the illness and the frequency at which they will manifest (Rabinowitz et al., 2009). There are divided opinions on how BPSD symptoms can be managed. Chen et al. (2014) and Oliveira et al. (2015) suggested that a PwD's behaviour can be improved by changing the caregiver's attitude, personality, style of caring, and environment. The caregiver should create an environment that is suitable for the PwD. This environment should be a space that is visually familiar (with no major changes to reduce confusion) and relaxing, where the people who interact with the patient mirror the personality and coping style of the patient to avoid overwhelming emotional disruptions (Chen et al., 2014).

Conversely, several authors suggested that appropriate antipsychotic medication can alleviate the burden of BPSD (Aloysi and Callahan, 2020; Tan et al., 2020). However, some ICs avoid using antipsychotics because there is evidence that suggests the existence of dangerous adverse effects (Dyer et al., 2018). Other researchers point towards technology as a way to manage BPSD (Davison et al., 2016; Astell et al., 2010; Kerssens et al., 2015). These studies proposed the use of personal computers and tablets to provide the PwD with an interactive interface where they can see photographs, videos, or listen to audio from their family members that will help them reduce the symptoms of agitation and aggression. In another study, a useful piece of technology that was mentioned was GPS or an indoor navigator in the form of a pendant or wristband, which can be helpful when a patient wanders outside of their home (Bosco & Lancioni, 2015).

Notwithstanding this, in all the three explored approaches – changing the ICs' attitude, style, and personality – the use of antipsychotics and technologies proved to have a minimal effect on the BPSD symptoms across diverse studies (Cheng et al., 2012; Onishi et al., 2005; Tan et al., 2020). Therefore, they cannot be considered as a reliable way of managing a patient's BPSD.

Dealing with ambivalent feelings

The third identified challenge was processing the ICs' ambivalent feelings throughout the experience. The concept of ambivalent feelings within the caregiver literature is defined as the experience of having concurrent contradictory, conflicted, and torn feelings about the care recipient (Schneider and Schwarz, 2017). Only until recently have ambivalent feelings been considered as a challenging part of the dementia care experience. Before this, authors used to individually acknowledge negative and positive feelings emerging from the caregiving experience as challenging (Yu et al., 2018; de Labra et al., 2015; Farina et al., 2017). AboJabel et al. (2020) explained authors used to report positive and negative feelings separately rather than simultaneously because previous studies did not reveal the complexities of dementia care within intergenerational families (that is, the adult child relationship with parents). This type of family relationship traditionally engages in reciprocity or familism values (Rodriguez Rodriguez, 2013). Thus, intergenerational families expect adult children to care for their parents when they are ill or elderly. Studies of caregivers with intergenerational relationships revealed that caregivers with healthy relationships experienced higher levels of ambivalent feelings because their cultural values and burdensome experiences conflict (von Humboldt et al., 2018). The present study investigates Mexico, a country that has the embedded cultural value of familism and that commonly practices intergenerational relationships (e.g., grandparents, parents and children live together) (Cauce & Domenech Rodriguez, 2002). Therefore, since this study needs to understand the complexities of lived experiences of Mexican ICs using ATs during the care of a family member with dementia, it seems appropriate to explore aspects of the caregiving experience like ambivalence as exemplified in existing studies such as the one from AboJabel et al (2020).

The literature on ambivalent feelings of ICs of PwDs has been explored with researchers using both quantitative and qualitative methods. As an example of quantitative studies, Losada et al. (2016) evaluated the ambivalent feelings of 401 dementia caregivers in Spain using the Caregiving Ambivalence Scale (CAS) to measure the quality of the psychometric properties of the scale. Their findings suggested that the scale is suitable for dementia caregivers, however, they encourage further studies to confirm their results. In a similar vein, AboJabel et al.'s (2020) study aimed to test the validity of CAS to measure the ambivalent feelings of dementia caregivers from different ethnocultural affiliations, namely, Jewish and Arab. They analysed 370 ICs of PwDs from Israel (55.3% Jews and 44.7% Arabs). Their findings indicated that results are suitable to measure ambivalent feelings from different ethnocultural affiliations. Both of these studies reported positive results with their selected samples. It is important to highlight that in both instances these were the first studies to evaluate the validity of CAS for dementia caregivers. Therefore, regardless of the positive outcomes, they reported it is necessary to encourage further research to confirm their claims.

Moreover, Shim et al. (2012) used a qualitative approach in which they interviewed 21 ICs who were spouses of PwDs. The aim of the study was to compare the positive and negative feelings that emerged during their experience as carers. They found that participants reported ambivalent feelings as opposed to only positive or negative ones. Santos et al. (2013) interviewed 18 ICs about dementia awareness and their motivations to care for a PwD in Brazil using a phenomenological approach. Their results suggested that religion and social representations of what a family should look like influenced the participants' awareness and motivations. They concluded that cultural views and social opinions conflicted with the ICs' physical and emotional states, leading them to develop ambivalent feelings about the experience. Although both of the previous studies were, in essence, completely different, they both found the presence of ambivalent feelings in their respective investigations. The first study was conducted in the USA and the second one in Brazil. These are two nations with different cultural and social values and complex ethnic groups. Therefore, finding the same stressor within their samples suggests that the psychological wellbeing of the IC plays a fundamental role in the experience.

In summary, these studies revealed that there is a need to research further ambivalent feelings of ICs of PwDs. In particular, there is a need to examine if there is a correlation with higher levels of ambivalent feelings of ICs from different cultural contexts. By exploring other cultures, policymakers could potentially change their support interventions for ICs. Finally, there is evidence that the measuring tool CAS works well with quantitative studies, however, future research should explore whether this would be suitable for mixed methods. The next section contains a description of the different types of caregiver burden that were found in the literature.

2.3.3 Caregiver burden

In this section, there is an introduction to the concept of caregiving burden and its different types. The aim of the researcher is also to explore the literature on the factors that contribute to this phenomenon. Caregivers' burden has been studied extensively for the past 60 years (Yin et al., 2002). According to Kim et al. (2012), caregiving burden is "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual" (p.846). It is an accumulation of diverse factors that bring stress, difficulties, and challenges to a person that is taking care of someone who is either ill or dependent for a prolonged period of time.

There is a lack of studies that explore Mexican informal caregivers' burden (Robledo et al., 2012). Arévalo-Flechas (2008) suggested that in the Spanish language there is no word to translate the connotation accurately, where the word 'burden' is used in the literature. She explained that the closest translation to 'burden' is the word 'carga', which in English means load, not an emotional state, which is the way the word burden is usually used. She concludes that because of this, the perception of burden is different due to the linguistic incongruences that surround the terminology. The caregiver's ethnicity and their cultural values influence their perception of caregiving burden (Arévalo-Flechas et al., 2014). Caregiving burden is directly affected by the ICs' environment, beliefs, values, birthplace, and race (Knight et al., 2002). Thus, caregiving burden is a socially constructed concept.

Caregiving burden can be perceived subjectively and objectively (Wang et al., 2014). Cao and Yang (2020) described subjective burden as the feelings or emotions that derive as a response to the act of caregiving. In contrast, Hughes et al. (2014) defined objective burden as the tangible disruptions, time invested, and actions that may disturb a family or personal routine as a consequence of their caring responsibilities. From these forms of perceptions, caregiver burden is divided into three main types: physical burden, psychological burden (both classified as subjective), and financial burden (classified as objective) (Romero-Moreno et al., 2016; DaDalt et al., 2016). The following subsections contain an exploration of each of these three types.

Financial Burden

Collins and Swartz (2011) described financial burden within dementia care as the monetary expenses (for example, medicines, food, and medical bills) and work-related adjustments (for instance, leave of absence and loss of promotions) that a caregiver has to endure to provide for the caring needs of the affected family member. The literature highlighted three circumstances that increase an ICs' financial burden: 1) assuming the role of legal and financial decision-maker (that is, making decisions by proxy) of the PwD; 2) having to reduce or quit working; and 3) a lack of governmental support. These circumstances are described within this subsection.

The first circumstance unfolds when the PwD shows a significant cognitive decline. At this point, the PwD becomes incapable of dealing with their own finances and as a consequence, the IC needs to take over their monetary affairs (Widera, 2011). The vast majority of ICs are the PwDs' children or spouses (Kahn et al., 2016). DaDalt et al. (2016) explored the overwhelming feelings of financial burden in female spouses who had to deal with their husband's finances (for example, paying bills, taxes, and so forth). In their study, they concluded that people who experienced this imposed responsibility encountered higher levels of burden compared to females who had previously experienced others' financial responsibilities. Shepherd et al. (2019) suggested that ICs failed to judge accurately when they could start managing the PwD's financial endeavours as proxy decision-makers. However, it is common that ICs feel stressed and overwhelmed, increasing their perceived caregiver burden when assuming the role of their PwD's decision-maker, namely, being the proxy decision-maker (Ploeg et al., 2019).

The second condition that triggers financial burden is when ICs are forced to reduce their working hours, which leads to having a lower income (Heitmüller & Inglis, 2007). They often have to find a part-time job to have more money (Longacre et al., 2016) or quit their current job because caring tasks become overwhelming (Gautun and Hagen, 2010), and pay for out-of-pocket expenses like medicine and medical studies, among other things (Paraponaris et al., 2012). Previous studies suggested that ICs with a low income experienced higher levels of burden and a more negative perception of life than those who earned more money (Andrén & Elmståhl, 2007; Cao and Yang, 2020; Herrera et al., 2016). Ton et al. (2016) explained that financial burden has proven to increase when the PwD's caring needs become more specialised, consequently increasing their medical expenses.

The last triggering condition is a lack of governmental support. Andrén & Elmståhl (2007) explained that countries with pensions, financial support, or a welfare system can reduce the level of financial burden of ICs. For instance, in Europe, laws have been placed that provide ICs with an allowance or cash benefits, depending on the country, to alleviate the financial burden of caregiving (OECD, 2011). In LMIC like Mexico, there is no income support for caregivers, making the balance between work and caring a difficult task (Robledo et al., 2012). This situation makes ICs from LMIC rely solely on their family members, leading them to experience a collective sense of financial burden (Herrera et al., 2016). The following subsection has an introduction to psychological burden which is considered to be subjectively perceived.

Psychological burden

The concept of psychological burden has been described as the emotional strain and distress that an IC endures as part of their caring role (Chiao et al., 2015). Three main elements were identified in the literature as the most common psychological burdens: 1) stress, depression, and anxiety; 2) double-care responsibilities; and 3) feelings of grief. All three elements are described below.

The first component was the accumulation of emotional strains, namely, stress, depression, and anxiety (Romero-Moreno et al., 2016; Ho et al., 2016). The literature indicates that these emotional strains develop when ICs struggle to manage their PwD's BPSD (as described in section 2.3.2) and when they lack coping mechanisms (Lloyd et al., 2019; Oliveira et al., 2015). Harding and Peel (2013) suggested that when a PwD's BPSD becomes difficult to manage, this situation brings an enormous amount of stress and confusion to the IC. They also explained that ICs who are unable to understand what dementia is and tend to take the PwD's behaviours personally, putting a strain on their relationship. Band-Winterstein and Avieli (2019) revealed that psychological burden was often higher in ICs that had a difficult relationship with their PwD. This often results in guilt and shame, making the IC more likely to develop depression and anxiety (Oliveira et al., 2019). Furthermore, Sallim et al. (2015) suggested that females have a greater probability of becoming depressed, anxious and/or stressed while being an IC than males. They explained this happens because of the embedded household and caregiving tasks, namely, double-care responsibilities, which men tend not to have.

This brings us to the next element of psychological burden – double-care responsibilities. Double- care responsibilities (also known as the Sandwich Generation) refers to the experience where an individual has to deal with caring for two generations at the same time, such as their own children and their parents (Neal and Hammer, 2009; Brody, 2003). Contributing factors to this situation are a decline in fertility, delay in marriage and childbearing, the growing ageing population, higher life expectancy, and the continuous financial support of children 18 or older (Spillman & Pezzin, 2000; Riley, 2005; Sinha, 2013; Parker & Patten, 2013). Calvano (2013) studied the tensions between being an IC and having double-care responsibilities. She described that ICs who experience this are often psychologically burdened with mixed feelings about their role since they find it hard to become their PwD's (in this case their parent's) full-time carer. Duxbury et al. (2011) conducted a study of the levels of emotional strain of ICs who cared for an older adult. They concluded that ICs with double-care responsibilities living with both their children and dependent parent reported less burden than those who lived without their children. They explained that ICs who fell under this category reported being helped by their children with the different duties of their caring role.

Furthermore, the third element that contributes to psychological burden is grief. In the literature, two types of grief are outlined, namely anticipatory grief and ambiguous loss (Chan et al., 2013). The concept of anticipatory grief is often described as a syndrome that occurs because a person is unconsciously preparing for an imminent life change (Lindemann, 1944). He also described this preparation as a way of safeguarding oneself from the shock that occurs during or after the news of the death. Anticipatory grief has also been described as the stages and/or feelings of grief that a person goes through prior to an actual loss (Sweeting and Gilhooly, 1990). Chan et al. (2020) stated that having a close relationship with the PwD and feeling confused about one's own identity are considered the precursors for anticipatory grief. The concept of ambiguous loss refers to the process in which ICs physically see their PwD but are processing, in parallel, the reality that their loved one's cognitive abilities are progressively deteriorating (Boss, 2009). Dupuis (2002) explained that this is a type of loss that confuses people because it is incomplete and full of uncertainty for the families affected by it. In the next subsection, there is a description of the identified physical burdens that are to be considered to be perceived subjectively.

Physical burden

Schulz and Sherwood (2008) explained that physical burden can be attributed to the physical discomfort that develops as a result of exposing the body to highly demanding activities (for example, having bruises, cuts, or inflammation). They also described that it can be attributed to an imbalance of the body's health in which a person is malnourished, dehydrated, or exhausted, limiting the body's capabilities. According to the Alzheimer's Society (2015), examples of physical burdens are carrying the PwD around the house, exhaustion while supervising the PwD constantly to avoid night wandering and self-harm, injuries that the PwD inflicts on the IC, and a fragile immune system resulting from the high levels of cortisol from the constant stress. Ortega and Miranda-Castillo (2014) suggested that another explanation for higher levels of perceived physical burden is that ICs invest all of their time and money in attending to the needs of the PwD, rather than their own needs. They also explained that most ICs report having no time or being unable to meet the available dates and times of medical doctors (when they need medical care). Therefore, their own health needs are neglected and their physical burden increases.

The next section consists of a description of the different support interventions found within the literature and how they support ICs in their journey as dementia carers.

2.3.4 Support interventions

In this section, the researcher examines the different types of support interventions that are known for dementia caregivers within the literature. The aim of this section is to report the different support interventions on a country-by-country basis, to highlight the variety of approaches and research interests that exist. Support interventions are described as the different services that are provided by healthcare professionals, governmental entities, charities, and/or support groups (for example, other informal caregivers) that provide help in their trajectory as an informal caregiver (Cohen et al., 2000). Napoles et al. (2010) implied that the cultural background of an IC directly affects the way they will experience their caring role. Therefore, knowing that there are variances within each culture, it is important to distinguish what works for each to develop culturally appropriate support interventions. This should be of great importance to policymakers and healthcare professionals in order to provide better solutions to the issues caused by increasing numbers of dementia cases. Four main categories of support interventions for caregivers were identified in the literature: education and advice, social support, self - management, and professional support (Clarkson et al., 2018; Carter et al., 2020). The following subsections will contain discussions of previous studies carried out in different countries that focused on evaluating their support interventions. The identified support interventions did not all involve technological elements.

USA. Easom et al. (2013) explored the impact of education and emotional support intervention for ICs of PwDs in rural areas in the United States of America. They recruited 85 ICs and conducted nine face-to-face and three telephone interviews over a six-month period. All participants answered a demographic questionnaire and a risk appraisal assessment. The data were analysed using paired t-tests. The aim of the study was to test the impact of GA REACH (Georgia Resources Enhancing Alzheimer's Health) – an intervention that has been implemented successfully around Georgia that focuses on measuring the ICs' levels of perceived burden, depression, and overall health. Their findings suggested that GA REACH was positively received by ICs in the rural region. All participants reported decreased levels of depression and burden and reported increased health.

Furthermore, Gaugler et al. (2016) aimed to assess if a specific support intervention for spouse carers of PwDs would decrease the levels of burden for adult child carers. The support intervention tool used was the New York University Caregiver Intervention (NYUCI). Gaugler et al. recruited 107 adult child carers of PwD that were tested every eight, 12, and 18 months using the NYUCI. The data collected were evaluated using a single-blind randomised controlled trial. Their results revealed that the NYUCI was a useful tool that could potentially be used to evaluate adult child caregivers of PwDs.

The last study was by Pagan-Ortiz et al. (2014), who developed and evaluated an online support intervention called “Cuidate Cuidador” that aimed to provide bilingual information for ICs of PwDs. The researchers’ main objective was to educate, enhance the ICs’ self-efficacy, provide social support, and reduce their caregiver burden. The online intervention was intended to reach the Spanish-speaking communities, namely Hispanics, that reside in the USA. This study was divided into two parts: developing a website and assessing the website. The website was created following a formative evaluation that consisted of 23 ICs focusing on the usability, appeal, and communication of the tool. These participants were then interviewed using a focus group to provide feedback on the website. Once the website was improved, the second part of the study was conducted with participants from three countries: the USA, Mexico, and Puerto Rico. A sample of 72 Spanish speaking ICs of PwDs who identified with the Hispanic ethnicity were recruited. These participants were divided into two groups to test the tool: a control group that followed two sessions or an intervention group that consisted of four sessions. After the ICs’ set of sessions ended, they completed surveys and participated in a focus group. The qualitative results from this study suggested that the Hispanic community responded positively to the online support intervention and would be happy to continue its use. The quantitative results revealed that participants believed that using this tool could decrease their sense of isolation and increase their self-efficacy.

These studies revealed that the USA has a tendency to focus on support interventions that enhance education and emotional support for ICs of PwDs. Two of these interventions were face to face and one was delivered online. It can be argued that research in the USA focuses on evaluating existing measuring scales in groups that are considered difficult to reach, such as people in rural places and Hispanics. Perhaps, this measured approach reflects the new wave of research that is shifting their focus to under-explored territories.

United Kingdom. Bailey et al. (2017) evaluated the adequacy of pre and post for both types of interventions: face-to-face Cognitive Stimulation Therapy (CST) sessions for PwDs and the benefits of support groups for their ICs. CST sessions are cognition-based therapies for PwD that were designed by experts in the field of psychology after two Cochrane reviews (Spector et al., 1998a,b). In the reviews, Spector et al. found evidence that 45-minute group sessions, twice a week , focusing on themes (such as childhood, hobbies, and so on) could reduce depression and anxiety in PwD.

Bailey et al.’s (2017) analysed a sample of 12 ICs to review if the CST sessions were improving the quality of life of the PwDs and eight ICs for the support group intervention. For both groups of ICs, they used one-to-one in-depth interviews and used a mixed methods quasi-experimental

approach to measure the level of satisfaction and burden in spouses and adult children of a PwD. Their conclusion was that for the quantitative side of the study, there were no statistical differences between the pre and post phases of both interventions. However, their qualitative results suggest that only a few of the ICs felt that their PwD's quality of life had improved, but all the ICs from the support group expressed satisfaction with their sessions.

Similarly, Charlesworth et al. (2016) conducted a two-part study that focused on evaluating the effectiveness of pre and post intervention of reminiscence therapy (namely, professional support) and one-to-one peer support (social support) for ICs and their PwD. Reminiscence therapy "involves discussing events and experiences from the past" to evoke memories and improve well-being (Spector et al., 1998b, p.5). For the therapy trial, they recruited 194 ICs and 145 ICs for peer support. The study adopted a factorial pragmatic randomised trial approach that measured the quality of life, anxiety, depression, and loneliness from the participants. Their results concluded that neither reminiscence therapy nor peer support were sufficient to improve ICs' quality of life.

These two studies reflect how in the UK, professional and social support are the main areas of research on interventions for ICs of PwDs. Another important observation is that in both studies, the support interventions were conducted face to face as opposed to online. It can be argued that the participants from Bailey et al.'s (2017) and Charlesworth et al. (2016) are more resistant to use web-based tools than to one-to-one interventions.

Netherlands. Boots et al. (2016) developed, implemented, and evaluated a web-based self-management intervention for ICs. Their online intervention focused on increasing the ICs' sense of self-efficacy and goal completions. The researchers recruited 18 ICs and conducted in-depth interviews and a focus group to examine the opinions and efficiency of the intervention. They found that participants enjoyed the convenience of using the support intervention at home. However, participants experienced various problems with the online platform that resulted in negative feedback about the ease of use. Overall, their results suggested that ICs of PwDs need tailored support through each stage of dementia.

Dam et al. (2017) conducted a pilot study to evaluate the feasibility of developing an online social support intervention. The intervention was a web-based platform called Inlife, that allowed caregivers to browse information and encouraged social support through positive interactions. The Medical Research Council (MRC) framework was used to develop Inlife. Within this framework, three forms of data collection were followed: semi-structured interviews with ICs, focus groups with experts and web designers, and think-aloud tests for ICs. For the study, 25 ICs of PwDs were

recruited; they, together with the researchers, co-designed the platform and later on, assessed it. The conclusions of the pilot study were that participants found the interface difficult to use and therefore, preferred to use it sporadically. The researchers suggested future recommendations that highlighted the importance of a user-friendly interface.

The reviewed studies shed light into the vanguard movement of online-focused support interventions in the Netherlands. Both studies aimed to evaluate different types of support interventions, however, it is important to highlight that in both cases, the feedback hinted at major flaws in the interface design. This could be interpreted as an opportunity to encourage the research community to focus their attention on better designs for dementia care. Notwithstanding this, it can be concluded that from the studies of Boots et al. (2016) and Dam et al. (2017), ICs support interventions were aiming to increase and create tailored online-based interventions that could fit into the busy lives of the ICs that participated in those studies. It can be argued that these studies could further delve into how to create better user interfaces and explore the different technological needs that ICs under this cultural context need. The following two countries are cases of interventions from LMIC. These studies used the same trial intervention with the same objectives. Therefore, they are described concurrently.

Peru and India. Two studies were conducted in two separate LMIC, namely, India (Dias et al., 2008) and Peru (Guerra et al., 2011), with the aim of testing the appropriateness of the support intervention designed by the 10/66 Dementia Research Group (10/66 DRG) called 'Helping Carers to Care'. This project was created by the 10/66 DRG as a response to the findings of 24 studies that revealed high levels of caregiver burden in ICs of PwDs from various LMIC. The intervention was specifically developed for ICs of PwDs to be implemented at home. Randomised control trials were used in both studies, and the researchers separated the participants into two groups: the participants that received the intervention immediately after recruitment and the participants that had to wait six months to receive the intervention. Before and after each of the sessions, the researchers measured the participants' general health, level of caregiver burden, general distress, and activities of daily living carried out for the PwD. The data collected from both studies were analysed with a mixed effects model.

Dias et al. (2008) were a group of researchers that developed 'Helping Carers to Care' and tested it for the first time in India. Their study focused on reducing caregiver burden and improving ICs' mental health. The researchers recruited a sample of 81 ICs of PwDs, however, only 59 participants finished the six-month trial and 18 died during the duration of the study. Their study concluded that ICs' levels of caregiver burden and distress decreased significantly in both groups as a result of the intervention.

Guerra et al. (2011) evaluated the effectiveness of 'Helpers Carers to Care' to increase ICs' education and training on the subject of dementia in Peru. They recruited 130 ICs of PwDs that agreed to commit to a study length of six months to see the pre and post outcomes of the intervention. The intervention sessions were distributed over five weeks with a duration of approximately 30 minutes. The results revealed that there was no significant improvement in the quality of life or mental health in either of the groups after six months. They further concluded that more studies are needed to validate their results, and also that larger samples are needed.

These two past studies shed light on the fact that in LMIC, there is a need for support interventions since there were very few studies found on this topic. It is important to highlight that Dias et al.'s (2008) study was the first study in an LMIC on this topic. The focus of both studies was on measuring quantitative scales because they did not know if the same parameters would work for LMIC. The next support intervention was the only one found for Mexico.

Mexico. Villareal-Reyna et al. (2012) conducted an eight-week study with ICs of PwDs to examine which support intervention, namely cognitive conduct, laughter, or a mixture of the two, were more appropriate for Mexican caregivers. The study aimed to explore which type of support intervention would give ICs better coping skills and decrease their anxiety levels. With a quasi-experimental design that had a sample of 46 Mexican ICs, they divided them into four groups, three experimental, and one control group. The control group were given seminars about safety at home. The data collected were analysed using SPSS to determine which intervention was more effective. Their results revealed that the most effective intervention was cognitive conduct. They disclosed that the ICs that participated were only female and concluded that further research would be needed to evaluate how these interventions would work with men.

The previous study represents the only research attempt that has been conducted in Mexico to test non-technological support interventions. This study highlights a gap within the literature that proves the need for more research in LMIC, more specifically in Latin American countries, since figures suggest that by 2040, the number of dementia cases will increase to 71% (Ferri et al., 2006). This argument opens the door to future research in LMIC where it would be interesting to also test qualitative and mixed methods to evaluate support interventions in the future.

This section contained evidence of the different types of support interventions for ICs of PwDs in six specific countries: the USA, the UK, the Netherlands, Mexico, India, and Peru. These nations were selected based on the high number of studies found within high-income countries, namely the USA, the UK, and the Netherlands. For the specific cases of India, Peru, and Mexico, the selection

was made because they were the only studies in LMIC in this area of research. The need for studies in other countries is emphasised by this gap to create an awareness of the need to develop appropriate support interventions for ICs from LMIC. The aim of the next subsection is to identify the main areas of interest within ICs of PwDs in LMIC.

2.3.5 Areas of interest within ICs of PwD in LMICs

This subsection has an outline of the identified areas of interest within the ICs of PwDs in LMIC literature and the intention is to illustrate the different needs and challenges that exist for ICs that reside in LMIC. The identified areas of interest were: ICs' awareness of and education in dementia, identifying predictors of high-risk for informal caregivers' health and wellbeing, and developing appropriate support interventions. In the first two subsections, previous studies are presented to aid the arguments, whilst the last subsection contains a discussion about the two main views on how support interventions should be developed in LMIC (see section 2.3.4 for the identified support interventions from LMIC).

Dementia-awareness and education

The World Health Organization (WHO) stated in 2017 as part of their "Global action plan on public health response to dementia" that culture- and community-specific approaches need to be developed and implemented in LMIC (WHO, 2017). They argued that this need emerged from the results of various studies on LMIC that showed how each country interpreted dementia differently. Thus, having a misconception of the concept of dementia makes ICs from LMIC more likely to associate dementia with stigma.

According to Fletcher (2020), there are people in LMIC who believe that developing dementia is a normal part of becoming older. He explained that this lack of awareness prevents people from getting diagnosed with a type of dementia. The growing numbers of underdiagnosed cases of dementia in LMIC are having an adverse impact on PwDs' human rights (access to health services) and quality of life (WHO, 2017). Dai et al. (2015) conducted a qualitative study that examined thorough in-depth interviews the perceptions of 46 Chinese ICs about the concept of Alzheimer's Disease. Their findings revealed that ICs saw dementia as a normal part of old age and that the term Alzheimer's Disease (laonian chidai) has a derogatory connotation related to ageism in the Chinese population. Similarly, Mushi et al. (2014) explored the socio-cultural beliefs that ICs from Tanzania had about dementia. They conducted 25 paired interviews with ICs and their PwDs. Their results echoed Dai et al.'s as Tanzanian ICs saw dementia as a normal part of being older. They also found that dementia was commonly referred to as the "disease of old people" (ugonjwa wa uzeeni). However, this was not reported with a negative connotation. Both of these studies illustrated how different cultures associate dementia with ageing. Johnston et al. (2019) suggested

that people in LMIC relate dementia to old age because some of the behaviours from PwD, such as forgetfulness, are also considered normal in healthy older adults.

Another misconception was the belief that PwDs were cursed with the disease, being punished for a previous life, or had a connection to the spiritual world (Johnston et al., 2019). Mkhonto and Hanssen (2017) explored the beliefs that dementia is connected to witchcraft in South Africa. In their qualitative study, they analysed transcripts from interviews from a larger study using a hermeneutic approach. It was suggested from their findings that this socially constructed idea of dementia as witchcraft prevented PwDs from obtaining the appropriate help since their ICs felt fear that their family might be targeted with violence and hate. Willis et al. (2018) examined the experiences of PwDs in Pakistan. The aim of their qualitative study was to understand stigma and the role of Islam in dementia. Through their findings, they revealed that people perceived dementia as a curse from black magic or a sign that the PwD was close to death. This belief makes family members, just as in the study from Mkhonto and Hanssen, delay diagnosis and create a stigma around the illness.

In this section, there was an outline of the common misconceptions around dementia that exist in LMIC. It was stated that the prevalence of stigma around the concept of dementia prevents the people affected by it from obtaining proper care. The identified misconceptions were the belief that dementia is a normal part of ageing and that being affected with dementia has a spiritual or divine explanation. It is clear that addressing this issue is critical for the future of LMIC. If governments and healthcare systems ignore dementia awareness and discredit the need for people to be educated about dementia, more PwDs will be at danger of being denied proper care and ICs will continue to be at risk of experiencing caregiver burden. Thus, empirical research that investigates cultural contexts and their complexities in LMIC should be prioritised. The next section comprises a discussion of the need to identify the predictors of high risk for ICs' health and overall wellbeing.

Predictors of high-risk for ICs health and well-being in LMICs

It has been well documented that dementia care is a challenging experience (Wang et al., 2014). In LMIC, support interventions, formal care for PwDs, appropriate dementia screening tools, and prevention plans are lacking (Thrush and Hyder, 2014; Ferri and Jacob, 2017). As a consequence, family members are being forced to adopt the role of ICs and sacrifice many areas of their life, including their own mental and physical wellbeing, to care for their PwD. Ferri et al. (2011) stated that paucity of research has forced LMIC to adopt inappropriate interventions and for researchers to assume that the challenges faced in LMIC are the same as high-income countries (HICs). It has

been suggested by Gitilin et al. (2015) that being an IC of a PwD in a HIC can elevate the risks of caregiver burden, suicidal thoughts, and health deterioration. Notwithstanding this, the predictors of high risk for ICs' health and wellbeing in LMIC are currently not being studied sufficiently. Only two studies were identified that highlighted the predictors in LMIC.

Wang et al. (2014) conducted a study in China to examine the factors that had a detrimental impact on the dementia informal caregivers' overall wellbeing. As part of their qualitative study, they interviewed 23 informal caregivers of PwDs and analysed their transcripts with a double hermeneutic approach. Their findings were that Chinese ICs felt *endangered by the BPSD* of their PwDs. Their participants also reported high levels of caregiver burden that derived from the limited support of family members and the lack of useful support interventions.

Tapia Muñoz et al. (2019) studied the predictors of unmet needs of PwDs and the wellbeing of their carers in Chile. In their paper, they stated this was the first study in Latin America assessing the needs of PwDs and the wellbeing of their carers. They conducted a cross-sectional study in which they interviewed and administered a single questionnaire to 166 PwDs and their caregivers separately. A statistical analysis was carried out to determine the PwDs' unmet needs and the high-risk predictors of ICs' health. Their results indicated that adult child ICs experienced higher levels of anxiety and depression. It was stated that the elevated results of the adult child ICs were a response to the overwhelming challenges of their *double-care responsibilities* (as described in section 2.3.3). The unmet needs of PwDs were identified as being company and leisure activities.

The previous two studies indicated the high-risk predictors of ICs' health. The paucity of studies should be indicative of the imminent need for identifying the effects that dementia caregiving has in LMIC. The fact that the predictors in China and Chile were the only ones identified should be sufficient evidence to: 1) emphasise the need for more research; and 2) point out that these two cultures had very different results. In other words, just because countries are categorised as LMIC does not mean that solutions from another LMIC will work. Research could inform best practice and policy about predictors of high risks to design better interventions, increase dementia screening, and reduce the progression of dementia. Perhaps a starting point to identify LMICs high-risk predictors of ICs' health, could be to analyse previous studies (e.g., Hinton et al., 2019; Zhao et al., 2019; del-Pino-Casado et al., 2019) that have been conducted in HICs to see which elements could be replicable and evaluate if their results extend to LMICs.

Development of support interventions

According to Márquez-González et al. (2020), there are two general views in the literature regarding support interventions for ICs in LMIC. It is important to highlight that neither of these views are IT-driven or based. On the one hand, there are researchers that argue that successful support interventions from HICs should be protocolised and replicated in LMIC. Section 2.3.4 contained the few examples of studies following this approach (Villareal-Reyna et al., 2012; Guerra et al., 2011; Dias et al., 2008). On the other hand, there are researchers that suggest tailored person-centred interventions will be key to improving the ICs' quality of life. Their paper focused on endorsing the latter and it expanded on how tailored interventions have the potential to address the complexities of caregiver burden. For instance, their work references studies (Andrews & Williams, 2014; Johansson et al., 2012) in which researchers have reported a positive response from ICs. However, those two papers concentrate on ICs from HICs. Fletcher (2020) argues that this is one of the main issues around the discourse on support interventions for LMIC since only few studies, regardless of which view they adhere to or evaluate, have been conducted in HICs. Therefore, he suggested that research should focus instead on firstly discerning the main differences between carers from HICs and LMIC to identify the characteristics that could inform which approach would work best.

In section 2.3.1, it was stated that culture influences ICs' views and experiences in multiple ways. The argument stemmed from the impact that ethnic backgrounds have on culture. This view is highly relevant to the subject of support interventions in LMIC since it is important to assess and understand the differences that exist between each country's own ethnic groups (for example, Latinos, white, black, and so forth). This means that an IC's ethnicity informs their role and, therefore, attention should be given to understanding their lived experiences within a particular context to comprehend the intricacies and complexities of their care.

Farina et al. (2020) provided an important point for this discourse. They explained that studying specific characteristics from subgroups is essential, since many LMIC provide another level of complexity with the variety of indigenous groups that live there. To put this into perspective, they provided the example of Latin America and their 45 million indigenous people divided into many groups (for example, Mayan, Tolteca, Teotihuacan, and so on). Farina et al. stated that indigenous groups have specific perceptions of dementia and in addition, their cultural values are not compatible with those from other Latin American countries (for example, familism, marianism, and so on.). Thus, their views are consistent with Márquez-González et al. (2020) in that LMIC have a need for tailored support interventions.

This subsection highlighted the two main views within the literature on support interventions for ICs from LMIC; namely, protocolised and tailored interventions. Since there are only a few studies to sustain either view, the need to carry out further research in this area is encouraged. For the case of tailored interventions, it was also emphasised that this type of approach would provide researchers with a way to develop support interventions for ethnic and/or indigenous groups. In this way, governments and healthcare systems could potentially increase their awareness from such vulnerable groups.

2.3.6 Summary of The ICs of PwD

To summarise the main findings from this part of the literature review, ICs have a very important role in dementia care, their role is multidimensional, they have an important influence on the PwD and their culture impacts their role and experience section (Section 2.3.1). Three challenges of dementia caregiving at home were identified in Section 2.3.2: 1) home adaptations and domestic environment, 2) managing BPSD and 3) dealing with ambivalent feelings. There are different types of caregiver burden and these have implications for the caring experiences, these were discussed in Section 2.3.3. Previous studies have discussed the existing support interventions for ICs of PwD in different countries (as discussed in Section 2.3.4). There are a number of areas of interest in the literature of ICs of PwD in LMICs: dementia awareness, predictors of high-risk for ICs health and developing appropriate support intervention, which were discussed in section 2.3.5. The following section reviews the literature of assistive technologies (ATs) in dementia care research.

2.4 Assistive Technologies and dementia care

The aim of this section is for the researcher to present the different types of ATs and how they are used in dementia research. This exploration is divided into three main areas: section 2.4.1 briefly revisits the concept of ATs (as described in section 1.2.6) to highlight the differences between this term (AT) and intelligent assistive technologies (IAT). Section 2.4.2 consists of a discussion of the potential applications of ATs for dementia care. Section 2.4.3 progresses into a discussion of previous studies on ATs for dementia in LMIC. Finally, section 2.4.4 contains an examination of the different ethical considerations that have been raised by different experts in ATs for dementia research. For this section, the views of different authors were considered and explained (for a thorough description of how the literature review was conducted, see section 2.1). The work of lenca et al.'s (2017) was however seen to have particular resonance with this investigation, therefore specific emphasis was placed on that study in what follows.

2.4.1 The difference between ATs and IATs

Blackman et al. (2016, p. 3) defined ATs as “an umbrella term referring to specialized technology used by people to adapt how specific tasks are performed”. Similarly, lenca et al. (2017) stated that ATs are devices or systems that allow people with a specific disability to decrease dependency. These descriptions indicate that ATs enable people to live a more independent life and are supported by the AT to carry out day-to-day activities. In section 1.2.6, it was stated that ATs can be classified as low-tech and high-tech interventions (Bryant & Bryant, 2003). Low-tech interventions are devices that are non-electronic aids, such as a walking cane, whilst high-tech devices are automated and/or computerised, like hearing aids. ATs have the potential to support or complement physical (i.e., prevention of wandering, medicine management, fall prevention) and cognitive (i.e., orient, remind, communicate and alert) deficits of PwD (Jotterand et al., 2019). Two of the most common goals of these devices are to ensure the safety and security of the PwD (Gibson, 2019). ATs have the potential to maintain or increase the PwD independence and autonomy at home, since the devices can help to reduce the need to be in close proximity at all times to the PwD (Sriram et al., 2020). It has been suggested that the benefits of ATs extend to their caregivers because by, increasing the PwD security and safety at home, the caregivers' responsibilities are considerably reduced, thereby alleviating their stress and delaying institutionalisation (Beaudoin et al., 2020).

Intelligent assistive technology (IAT) is a specialised tool that connects an AT to a device with computation capabilities that connects through a network (Wangmo, 2019). lenca et al. (2017) stated that IATs can potentially be used for dementia care because these types of technologies cover a wide range of applications. These applications will be described in the next section.

Furthermore, when an IAT progresses into an integrated environment connected through a network, the technology then becomes an ambient assisted living (AAL) technology (Peterson et al., 2012). Blackman et al. (2016) explained that “AAL is rooted in the following: traditional assistive technologies for people with disabilities; universal design approaches to accessibility, usability, and acceptability of interactive technologies; and the emerging ambient intelligence (AI) computing paradigm, which provides intelligent, unobtrusive, and ubiquitous assistance” (p.2). It has been previously suggested that AAL technologies, just like ATs and IATs, have the potential to improve ICs’ and PwDs’ quality of life (Peterson et al., 2012; Godwin et al, 2013). However, the present study only focuses on ATs, since in Mexico, this was the only type of technology used by ICs of PwDs in their homes.

The similarities are clear since ATs, IATs, and AAL technologies are designed to assist, to a certain extent, a person with a disability to increase their independence and, as result, their overall wellbeing. It was stated that the difference between ATs and IATs is that IATs have computation capabilities that communicate through a network (Wangmo, 2019). As for the differences between IATs and AAL technologies, the latter focuses on enhancing the safety and comfort of a PwD with an integrated environment that is connected through a network (Peterson et al., 2012). The next section consists of a discussion of the different applications of ATs in dementia care.

2.4.2 Application of ATs in dementia care

Following the definition of ATs in the previous section, this discussion focuses on the current uses of ATs in dementia care. Ienca et al. (2017) suggested five different applications for dementia care: 1) ADL, 2) monitoring 3) physical assistance 4) cognitive assistance and 5) social interaction. The following subsections will describe each potential application and provide examples of studies that have been done for dementia care.

Activities of daily life (ADL). In dementia care, ADL are the common, repetitive and basic tasks that ICs need to assist PwD everyday with (Liu et al., 2007). For example, bathing, toileting, eating, providing medicine, among other activities. The literature shows that from all the possible ADL, only the ones with specific instructions, like taking medication at a specific time, could be managed through technology. It is common to have ATs that through a pre-recorded voice reminds the patient about taking their medicines (Bosco & Lancioni, 2015). Unfortunately, there are no technologies that could help in physical tasks like dressing, feeding, and bathing. However, it is possible to track the amount of times a PwD, in case of living by themselves, repeats an ADLs. Belley et al. (2014) created a distributed system to quantify the ADLs a PwD does in a day to recognise behavioural patterns and detect unusual activities. This system consisted of smart meters and smart analysers that identified the power consumption of appliances around a lab-based apartment. The appliances that they tested were the kettle, toaster, coffee maker, stereo

and microwave. Their results suggested that their prototype was successful and could be potentially used in dementia care to track ADL.

Monitoring. The focus of this category is on monitoring the PwD and reporting emergencies and accidents with technology around the house (Peterson et al., 2012). An example of this type of application is Sugihara and Fujinami's (2011) work with camera systems. In their study, they installed monitoring cameras in three houses of PwDs that lived with their IC. The aim of the study was to identify the positive and negative ways in which a monitoring system would affect ICs' stress levels. Their findings indicated that ICs felt less burdened once they adopted cameras into their routine since they were able to concentrate on more than one task at a time.

Physical assistance. These ATs are the ones that compensate for the motor and locomotive deficits in PwD (lenca et al., 2017). Mahoney et al. (2014) designed and developed a system for in-home use that would physically assist PwDs to dress. The system is called the 'Development of a Responsive Emotive Sensing System' (DRESS). In their study, they tested the audio and visual prompts from DRESS on healthy subjects and allowed ICs to observe how the system operated. Their results indicated that ICs accepted the prototype and that further testing was needed since one specific functionality, namely, trying on trousers, was unsuccessful on all attempts.

Cognitive assistance. This type of application comprises ATs that enhance cognitive functions for the PwD, for example, memory aids (lenca et al., 2017). These types of technologies are generally managed by the IC (e.g., loading photos, videos, games), but used with and by the PwD (Gibson, 2019). This means, that the IC can choose to be next to the PwD while using this technology and/or allow (while monitoring from afar) the PwD to use the technology alone (e.g., a PwD playing a game using a tablet). As an example of this, is the mobile app for tablets developed by Yamagata et al. (2013). They aimed to test the level of engagement and impact the app had on PwDs. Some of the features from their app included allowing the IC to store and view photographs, videos, and music, so that the PwD can be cognitively stimulated with memories. The findings of their study revealed that the majority of PwDs found it difficult to use the tablets and were easily frustrated when they exited the app by accident. They concluded that better designs and more user-centred approaches should be considered in future research.

Social interaction: These systems aim to initiate social interaction between the AT and PwD to decrease the ICs' burden of repetitive conversations and stimulate the PwD socialisation (lenca et al., 2017). An example of this type of application is the touchscreen videophone that was developed to enable PwD to make calls to their family members and/or primary caregiver (Boman

et al., 2014a). This AT aimed to facilitate social interactions between PwDs and their carers since literature suggest that PwD have difficulties handling ordinary telephones and visualising a person they are not physically observing (Boman et al., 2014b). The system consisted of a touchscreen monitor, a webcam at the top of the screen and a retro phone handset. Whenever there was an incoming call, the touchscreen monitor would display the photograph and name of the caller. To pick up the call, the PwD will only need to pick up the handset and to end it the user would need to hang up the handset like an ordinary phone. Although this study was only a mock-up, the findings from Boman et al.'s (2014a) results indicated that the videophone mock-up needed some functional changes (e.g., being able to disable webcam). Notwithstanding this, the observations from the study suggested that PwD understood and enjoyed the AT.

All the presented applications and studies provided a glimpse into what could be the future of technologies for dementia care. However, it is important to highlight that all the referenced examples are from studies in HICs. Therefore, these applications should first be investigated in LMIC to assess if the ATs from those regions fit with suggestions from lenca et al. (2017). The following subsection contains an overview of the different types of ATs devices found in the dementia care research literature.

2.4.3 Categorising ATs in dementia care

It has been revealed in the current literature that ATs for dementia care are growing exponentially. To put it into perspective, the number of new potential applications for ATs has tripled in the past five years (lenca et al., 2018). Therefore, as this area of research keeps growing, it is difficult to determine which categories to select from the pool of dementia care studies. For the purpose of this section, a combination of different views will be followed from the authors lenca et al., 2017; Gibson et al., 2016; Beauregard, 2019. Based on their reviews, the identified categories for the types of ATs in dementia care for this study were established as distributed systems, mobility, safety, and support activities. These specific categories were selected as the most appropriate for this study as they synthesise the systematic reviews from the aforementioned authors. It is important to clarify that most of the provided examples can fit into more than one category. In other words, an AT can have more than one potential application (for example, a mobility technology that also aims to support activities). Therefore, it seems appropriate to simplify the understanding of the following categorisations by arranging them into two taxonomies, namely enhancing independent living and improved life balance. The aim for naming taxonomies is just to help the reader understand the purpose of the selected categories at a higher level (e.g., how they relate to the IC and PwD and/or how they help them), since these were selected from a pool of authors. The first taxonomy is called enhancing independent living which contains the

categories of distributed systems and mobility. The second taxonomy, namely improved life balance, encompasses the categories of safety and support activities. The following subsections will contain descriptions of each type of category and will provide examples to aid the discussion, including the rationale behind each taxonomy. For the purposes of this review, studies that used ATs, IATs, and AAL technologies were included.

Distributed systems: According to Lenca et al. (2017, p. 1304), “a distributing system is defined as a system composed of several sensing and processing sub-systems, which communicate through a computer network”. In other words, these are the systems that share information to the other parts connected within the system network. An example for this type of AT is a passive sensor. Passive sensors are devices that do not emit signals but instead, only acquire signals, e.g. automatic faucets and toilet flushers (Golding and Lesh., 2001). Moreover, these type of technologies were arranged in the taxonomy of enhancing independent living because distributing systems assist ICs by informing them about any irregular behaviour or by automatically triggering an activity of daily life for the PwD that will aid the IC in their caring role (e.g., automatic blinds and smart vacuum cleaners).

Stavropoulos et al. (2014) developed a semantic web technology called DemaWare (now DemaWare2). This system places different sensors around the house and appliances of a PwD, to retrieve relevant information (e.g., sleeping patterns and physical activity), making it completely unobtrusive. Collected information is interpreted by the system, providing accurate information, like the location and actions of the patient, to caregivers in text messages. For example, the system could track if the patient ate all three meals by recording how many times the refrigerator has been opened. The second version, DemaWare2, included a unifying web service that interprets in real-time the videos and audios captured by cameras of the PwD’s sleep, physical activities, and daily tasks (Stavropoulos et al., 2017). In both versions of the system, the PwD is aware of the home setup (i.e., cameras and sensors), however, the PwD never interacts with the system. Stavropoulos et al. (2017) evaluated in a lab and home environment the effectiveness of activity recognition by analysing the anonymised video, audio and sensor recordings using a True Positive Rate (TPR) and Positive Predictive Value (PPV) measure, that focus in eliciting the recall and precision to evaluate the performance of the data. The results from their study hinted at a high percentage of recall and precision made by the system in the lab environment. Perhaps, a reason for this is that real life scenarios are not sequential and more prone to interruptions than a lab-based environment. Notwithstanding this, they recommend further testing in real homes since the most of their conclusions were from the lab-based environment results.

Haritou et al. (2012) formed the project ALADDIN which stands for ‘A technology pLatform for the Assisted living of Dementia elderly Individuals and their carers’. This project consisted of a web-based platform that allowed PwDs to answer questionnaires about their health, ICs to remotely monitor their PwDs, medical professionals to assess the PwDs’ cognitive state, and external services to provide cognitive games and social networking. ALADDIN was developed as a response to the lack of simple and user friendly systems to manage dementia. The main objective of ALADDIN is to provide dementia caregivers with a way to manage the symptoms of the PwD safely in their home environment (Haritou et al., 2012). The platform helps all end-users to assess risk and support decisions about the PwD. For example, a PwD physiological information could be retrieved by medical professionals to assess the progression of their dementia. ALADDIN is being tested in three countries by more than 30 end-users. Future work is needed to evaluate the effectiveness of this tool in a real-life scenario since it has just been tested in a lab-based environment.

Mobility aids: As mentioned in section 2.3.2, mobility is an important part of dementia caregiving since reducing mobility and enhancing sedentarism in a PwD could potentially increase the progression of their dementia (The Alzheimer’s Society, 2015). The previous argument is not trying to generalise that all PwD have a mobility impediment, but rather to emphasise that as the disease progresses their physical and cognitive health eventually declines. Some PwD might be impeded in their mobility more than others in different capacities (e.g., pain while walking, unable to move one arm and so forth) and in different stages of the disease too (Alzheimer’s Society, 2017). Moreover, this category encompasses all ATs that facilitate the mobility of the PwD (lenca et al., 2017). The help provided to the PwD facing mobility issues can be by independently using the AT by themselves or with the help of their primary caregiver (Alzheimer’s Society, 2015). Some examples of ATs within this category are powered wheelchairs, scooters, assistive stair technology, and exoskeletons (Beauregard, 2019). This category belongs to the taxonomy of enhanced independent living since it aims to increase the PwD independence, which as a result reduces the caregivers’ participation in physical burdensome tasks (e.g., carrying the PwD).

How et al. (2013) created an add-on for powered wheelchairs – the Intelligent Wheelchair System (IWS). The aim of this AT was to reduce and prevent wheelchairs hitting obstacles (such as rocks) and unstable surfaces with the help of motion sensors and navigation assistance. They divided their study into two parts, where they tested different environmental conditions and carried out user trials with older adults with cognitive impairments. For their study, How et al. (2013) recruited from a long-term nursing home older adults who were 60+ years of age and scored 11-26/30 in a Mini-Mental State Exam (a screening test to establish the level of cognitive impairment) that was performed by

specialised nurses inside the nursing home. The results from their first experiment revealed that IWS was safe and accurate for use in institutional settings since in all the tested categories IWS performed successfully. For their second experiment, their findings indicated that IWS was superior compared to previous wheelchair systems. Therefore, they concluded that IWS was a safe option for PwDs to increase their mobility.

Hsieh et al. (2016) developed an AT called i-Go to aid the mobility of PwDs living at their own home or with other family members. The design was a robot walking assistant that aimed to prevent any type of collisions using laser sensors and control modules. The mobility robot was developed to provide motion assistance for PwD to increase their safety and independence indoors and outdoors. The AT looks like an electric scooter, contains force-sensing grips and laser sensors that are configured to transport a PwD safely. The technology was programmed to detect and avoid moving and static obstacles. The three strategies to avoid collisions were: guiding, waiting, and steering. In theory, the PwD can direct the technology, however, if a sensor detects a hazardous situation (e.g., a moving obstacle) the i-Go will automatically reroute the PwD to the desired final destination. Although all the experiments that were conducted for this study were successful, they were all conducted in a controlled lab environment. Therefore, they concluded that more testing in different environments with real end-users should be carried out in the future to evaluate its efficacy.

Safety: This category focuses on preventing and reporting emergencies and accidents with the aid of ATs around the house. Monitoring systems are also considered part of this category because by monitoring a PwD, the IC can prevent an accident. Some examples of this technology type are fire detectors, pillow alerts, surveillance, motion sensors, emergency buttons, and GPS (Wolverson et al., 2019). This category belongs to the taxonomy of improved life balance because increasing the PwD home safety, decreases their caregivers burden providing them with more control in their caring role and life (Alzheimer's Society, 2015).

The SWEET-HOME project focuses on detecting and preventing dangerous situations around the house through the interconnection of smart appliances and sensors (Portet et al., 2013). This system has voice and touch recognition. Data from end users is collected via a set of microphones, speakers and sensors that are incorporated to the smart home environment. The data is then analysed and extracted in real time using specialised algorithms to identify any potential hazardous situations (e.g., the system checks oven is off at night, lights are on, and so forth). In an emergency, it triggers an automated voice to immediately assist the patient, whilst also reporting the incident to the appropriate emergency services.

Cavallo et al. (2015) developed a smart home network based on ZigBee wireless technology as part of the Alzheimer's Project in Italy, of which the aim was to ensure PwD's safety and comfort in their own homes. The system was developed out of the need for caregivers to provide care from a distance and to allow a PwD to live as independently as possible in their own home. Cavallo et al. (2015) stated the IC as the stakeholder that controls the system, whilst the PwD is just being monitored by different sensor around their home. The system possessed 45 different features including, but not limited to, recognising when the patient woke up or wanders at night and controlling access to cabinets with automatic locks. Examples of the smart components around the home are: a bed mattress and chair cushion with embedded sensors to detect presence and activity from PwD, door sensors that triggered an alert when they were opened and a portable GPS that was worn by the participant to localise their physical position (Cavallo et al., 2015). The data from the smart environment was directly collected by the multiple sensors and aimed to recognise the participant's behaviours and hazardous situations. This system is nonintrusive and notifies the caregivers in real-time about the patient's status. The results from Cavallo et al. (2015) suggested that the ICs were hesitant about the AT since they were unfamiliar with the system and its components. Changes on the user interface were part of the main feedback to the development team.

Yilmaz (2019) developed and implemented a context aware safety system for PwDs called iCarus. This non-commercial system monitors the PwD through sensors to manage their wandering behaviours. The system collects data from different strategically placed sensors (e.g., doors, bed, and so forth) around the PwD home, a smart watch and a smartphone used by the PwD. The output information is displayed to the IC directly on their mobile or computer, as long as they have access to the internet. iCarus notifies the IC (and if preferred emergency services) if the PwD moves outside a set parameter and warns the patient to return to their home by supporting audio navigation for the PwD. This system, unlike others, is novel in that ICs can create their own rules, through a user-friendly interface, to define new safe and harmful zones that can be established in the system. iCarus also has the capability of detecting the temperature in a room. This feature can also be programmed to the ICs' needs, for example, if the room where the PwD is over 25 degrees Celsius, a text message is sent to the IC so that they can take action. Yilmaz conducted a pilot study to evaluate the accuracy of the developed system within a controlled environment (i.e., a lab). The participants (not PwD and their carer) answered surveys about the novelty and use of iCarus. Overall, all participants were satisfied with the functionalities, however, some of them reported problems with their mobile connection. Further work is needed with real PwDs and ICs to evaluate its accuracy.

Support activities: ATs that fall into this category are those that allow the IC to train for caregiving related tasks and/or scenarios, and receive psychological support with technology (Gibson et al., 2016). According to O'Connor et al. (2014), online support groups, 3D virtual environments and virtual reality technologies have the potential to provide ICs with tools to keep a balance during their caregiving journey. This category belongs to the taxonomy of improved life balance because this type of technology allows the IC to care for their own wellbeing by receiving support, hence improving their life. For instance, O'Connor et al. (2014) conducted a pilot study to assess the feasibility of a 3D virtual online support group for ICs of PwD. The main aim of their investigation was to assess if the virtual environment reduced the ICs loneliness, depression and stress. O'Connor et al.'s (2014) solution consisted of a 3D virtual environment, featuring a cosy log cabin, where participants were free to explore and meet other carers in real time. In order to join the virtual environment participants were asked to create their own avatar to maintain anonymity and to allow them to feel less pressured about the presence of one-to-one video interactions with other carers. O'Connor et al.'s (2014) study consisted of testing the virtual environment in a period of 8 weeks with recruited ICs of PwD. During the online sessions, the participants were given a support intervention guided by a professional psychologist and were asked to complete a survey about their experience and a post-intervention survey (including UCLA Loneliness Scale, Geriatric Depression Scale, the Zarit Burden Interview and the Perceived Stress Scale). The results from their study suggested that ICs of PwD enjoyed the 3D virtual environment and showed a decrease in their levels of stress, depression and loneliness.

Fredericks and Kerns (2019) developed CARETAKVR, a virtual reality (VR) application that aims to train and expose ICs of PwD on different day to day scenarios and tasks that they might face during their caregiving experience (e.g., helping during a PwD fall, turning off the stove, and so forth). CARETAKVR was only developed as a proof of concept since there is not enough information that supports VR as a reliable tool for ICs. Therefore, Fredericks and Kerns (2019) work only provides a general description of the innovative AT which they state needs an improved gamifying environment, trained neural networks and the incorporation of simulated smart devices to improve the overall experience of users.

All the aforementioned categorisations and examples provide an insight into the realm of possibilities that for ATs aiding with dementia with. Just as was stated in section 2.4.2, these studies represent the views and developments made in HICs. Further research should focus on the validity that these categories have in LMIC or if their circumstances reveal a new set of usages. The next section will discuss the different ethical issues that are raised in the use of ATs for dementia support.

2.4.4 Ethical Considerations for ATs

This section contains an introduction of the current literature in ethical design and use of ATs, which is followed by a discussion of the harms that surveillance technologies pose to users since this was the most used AT by ICs in this study. Ethical considerations are a key element of any work that involves PwDs. Beauchamp's and Childress's (1991) ethical guidelines are often used as a guide for dementia research. These are beneficence, non- maleficence, autonomy, and justice. Beneficence refers to how a researcher should always strive to benefit or contribute to the PwD in a positive way. Non-maleficence emphasises the importance of never harming the PwD. Autonomy means that the researcher should always respect the PwD's or any participant's privacy, independence, and freedom of choice. Finally, justice refers to the responsibility of treating all PwDs fairly and equally.

Moreover, when technology is for and used by vulnerable people (in this case PwDs), ethical considerations about the design and development need to always be taken into account (Ienca et al., 2018). According to Stahl (2012) there are several specific conditions that need to be met when doing research and innovation in information systems in a responsible manner. The following list taken from Stahl (2012, p.209) condenses the ways in which responsible research and innovation (RRI) can be deployed in an ethical manner:

- “Develop legal or other regulatory systems that incentivise researchers, industry and organisations to engage with normative questions.
- Support mechanisms that will allow individuals and organisations who deal with this sort of question to find out about current norms and regulations, as well as good practice and successful solutions.
- Incorporate viewpoints and positions of a broad range of stakeholders.
- Recognition that responsible ways of addressing ethical issues are in the interest of the researchers and organisations who realise innovation.
- Development of reflective processes within research, so that norms, their context and application can be understood, predicted and influenced.”

Boger et al. (2019, p. 63) suggested the following points for ethical designs and uses of ATs for PwDs. It is important to note that these principles apply to technologies that were meant to be used and for both, the PwD and/or the IC. In other words, technologies that aim to assist the PwD for independent living and technologies that aim to increase the IC wellbeing should adhere to the following principles.

Respect autonomy and independence: This principle refers to the designers and developers making sure that the needs of the PwD are being considered for the technology. Designers and developers should also allow any of the stakeholders involved, namely PwDs, carers, family members, and so forth, to withdraw from the project at any point.

Decision-making and informed consent must be accessible to everyone: Designers and developers must gain informed consent from the PwD and their family members. If the PwD is not able to consent, then their carer should be well informed to make a conscious choice.

Uphold wellbeing: This means that the PwD's safety should be prioritised during all phases. In addition, the technology cannot and should not aim to replace full human contact or caring duties.

Periodically revisit decisions: The designers and developers should carry out their work in an iterative manner. This means that they should make sure that their artefacts fit the end-users' needs, and if not, they should be open to change since agreement is paramount.

The second part of this ethical review concentrates on discussing surveillance technologies. Surveillance technologies are defined as "any computing technology that allows one party to monitor the behaviour of another to modify behaviour in a specific way" (Jespersen et al., 2007, p. 113). According to Elger (2019), ATs with surveillance capabilities interfere with an individual's *privacy*. She argues that, at first glance, it could appear like interfering with a person's privacy poses no harm since it does not inflict physical harm. However, this should be taken seriously. For example, Astell (2006) argues that surveillance, in particular ATs that have the capacity to correct or guide a PwD, might seem to be dehumanising because the exerted control appears to 'train' or 'tell off' a PwD. She suggests that a more considerate way to tackle these views is by validating the PwD and their carer's needs and concerns about the technology. This means that the AT should prevent any confusion to both parties and avoid the feelings of infantilisation. Hughes (2008) offers another interesting perspective to the discussion. He points out that if surveillance is going to be implemented, all involved parties should consent to this and establish boundaries (for example, not having cameras inside the toilet). Otherwise, this would violate a person's independence and right to privacy that could potentially be illegal in different countries. However this depends on whether the PwD has the mental capacity to do so, or if they have family members or a caregiver who can give consent on their behalf (Berridge et al., 2019).

As a contrast, covert surveillance refers to "any surveillance that is carried out in a manner calculated to ensure that persons subject to the surveillance are unaware that it is, or may be, taking place" (Sheldon, 2011, p.197). Within the literature, the topic of covert surveillance is typically viewed as a variation or subset of surveillance technology studies since it is considered more of an

attribute of surveillance technology describing its discreetness among patients (Kubiak et al., 2019). In the case of surveillance systems that are intrusive (for example, bracelets and GPS), it has been argued that it makes PwDs *feel restrained* and/or *stigmatised* (Niemeijer et al., 2015; Astell, 2006). Ironically, it has been revealed in previous studies that one of the reasons that surveillance technologies are used is because carers want to prevent the need to physically restrain (for example, using sedatives, safety belts, and bed rails) their PwD (Evans et al., 2002; te Boekhorst et al., 2013; Niemeijer et al., 2011). Zwijnen et al. (2012) suggested that using wearable sensors allows carers to prevent their PwD wandering outside of certain perimeters, and reduces the need to constantly check on them. However, it has been reported that PwDs who are still able to consent perceive wearables as stigmatising (Astell, 2006). This feeling of stigma predominantly exists in cultural contexts where tagging is associated with criminals or animals (Lodha and De Sousa, 2019). Notwithstanding this, in dementia care, using electronic tagging and/or wearable devices is preferable to methods of physical restraint (Bail, 2003; Miskelly, 2004).

Another criticism of the use of surveillance systems for PwDs is the idea that the ATs are being perceived as a *substitution of care* (Beauregard, 2019; Ienca et al., 2018; Mahoney, 2019). Mahoney (2019) argues that since dementia is ambiguous and diverse, it is impossible to create a universal dementia profile that designers and developers could use to base their technologies on. As a consequence, dementia care needs to be tailored to the PwD's specific needs (Kenner, 2002). It has been argued that carers who aspire to use AT as a substitute for care need to learn more about the syndrome because PwDs need regular communication, mobility outside their home, cognitive stimulation, and to engage in leisure activities (Beauregard, 2019). All of these activities cannot be substituted with technology. Ienca et al. (2018) argues that independence and independent living should not be confused by designers and developers since evidence suggests an increase in technologies for in-home independent living. They state that although the intentions of independent living are noble since many governments and families are looking to reduce the need for institutionalisation, independence can increase the risk of isolation for the PwD. The "big brother" (passive monitoring through a camera) approach might lead to deterioration of the PwD's mental wellbeing because they need human interaction (Percival and Hanson, 2006). Therefore, it is considered good practice to define the goals of the AT and its capabilities around the PwD's needs when creating a new technology (Ienca et al., 2018). It has also been suggested that a way to prevent an insensitive AT is by urging designers and developers to understand the personal, social, and material contexts of the place where it will be implemented (Gibson, 2019). Finally, it is of great importance to consider the needs of PwD when designing surveillance technologies. Vermeer et al. (2019) suggested that future work is still needed to establish effective use of surveillance technology in dementia care because there are no studies that cross analyse the needs of the two stakeholders of this interaction, namely caregivers and PwD.

2.4.5 Summary of ATs and dementia care

This part of the literature review discussed the concept of AT and how it relates to other different known dementia technologies, such as IATs and AAL technologies (section 2.4.1). Five different types of applications for AT in dementia care were identified in Section 2.4.2: 1) ADL, 2) monitoring 3) physical assistance 4) cognitive assistance and 5) social interaction. In section 2.4.3, five categories for ATs in dementia care were selected from the views from various authors. The categories were established as: distributed systems, mobility, safety and leisure activities. Examples were provided from previous studies; however, it was stated that all were from HICs. There are a number of ethical issues around the use of ATs for PwD that were discussed in section 2.4.4. The following section reviews the literature on the current studies on ATs for dementia care.

2.5 Concepts related to human-technology relationships relevant to the caregiving experience

The aim of this section is to provide an introduction and context about the narrow area of research called experiential computing, in which everyday human experiences and technology intersect. It also will provide an explanation of the impact and the role that technology mediation plays in human experiences and the role of technologies in caregiving. This section is divided into four main parts: section 2.5.1 will define how the concept of experience, lived experiences and sensemaking are being used for the purpose of this thesis. Section 2.5.2 introduces the concept of technology adoption and technology appropriation. By understanding these concepts, it will help bridge the gap of the before, during and after experiences of the ICs of PwD who used ATs for their caring role. Section 2.5.3 introduces the reader to what is understood as human experiences with technology, the concept of technology mediation and what is postphenomenology within this context using two frameworks under this stream of thought.

2.5.1 Experience, lived experiences and sensemaking

The concept of experience is complex since it can, generally, be explained in three ways. The first view of experience, refers to an occurrence and/or situation that involves a particular person at a particular time (Gupta, 2006). For example, when someone tells you about their holiday. During that instance, the person is recalling their experience that occurred in a particular time. The second view refers to experience as a memorable moment. These are the types of experiences that are imprinted in someone's mind and become significant to a person (Smith et al., 2009). An example of a positive experience would be the birth of a child and a negative can be exemplified as the death of a loved one. Finally, the third view refers to experience as a reflective process in which an individual tries to

master something in their environment by engaging in the same activity numerous times until mastered (Dewey, 1938). For example, in order to become an athlete, a person needs to learn the technicalities of the sport and practice through repetitions in order to become an experienced athlete.

Furthermore, Gallagher (2012) suggested that the concept of experience can be interpreted using the philosophical lens of phenomenology (pertinent to this thesis). The fundamental principle of the philosophy of phenomenology is the “careful examination of human experience” focusing on illuminating the meaning behind those experiences (Smith et al., 2009, p.12). In this branch of philosophy, there are two main ways to approach the concept of experience. The first view derived from philosopher Merleau-Ponty’s (1962) description of the self and its relationship to the world. One of the major contributions of this body of work is the idea of an *embodied* experience (Bengtsson, 2013). Merleau-Ponty (1962) describes this notion by suggesting that people have a uniquely situated perspective on the world, he explained: “the body no longer conceived as an object in the world, but as our means of communication with it” (p.106). This means that, a person’s perspective (i.e., subjective experience) and their own embodied position (i.e., physical body) perceive together as one entity as they relate to the world. For example, a person attending a graduation ceremony as a viewer would have a different perspective than the person who is the graduate. They are both in the same room, experiencing the same ceremony, however, each one is perceiving the world differently since, in each person, their bodily senses and physical bodies are reacting differently. In the case of the attendee, the person will be experiencing the ceremony from a seated position. This physical position provides them with a visual amplitude of the stage and undivided attention of the graduands who are most likely seated in front of him/her. To add a layer of complexity to the experience, this attendee might be the parent of a graduate which will enhance the significance of the event. Moreover, in the case of the graduate, their experience will be completely different since other subjective factors, like walking on the stage, knowing when and how to reach for a hand shake, and so forth. Both individuals experienced the ceremony at the same time and place, but with a different perspective. For a fuller explanation of the concept of embodiment experience please refer to Merleau-Ponty’ *Phenomenology of Perception* (1962).

The second view originated from philosopher Heidegger (1962) who suggested that the idea of experience was bound to existentialism (e.g., questioning the meaning of life, death and truth). He introduced the expression of Dasein (translates to ‘there-being’), that in essence, means ‘being in the world’ or more colloquially ‘existence’ (Smith et al., 2009). In his words, “Dasein is essentially being-with... Even Dasein’s being alone is being with in the world. The other can be missing only in and for a being with. Being alone is a deficient mode of being with; its very possibility is the proof of this” (Heidegger, 1962, p. 156-157). This concept means that, in theory, human beings are always experiencing Dasein because the notion of ‘being in the world’, is simply humans interacting with other

humans and objects. Under this idea, people are always being in somewhere, participating in something and comporting in a specific way that is a reaction to how they are existing in the world (Ihde, 1990). For example, if a person studied a culinary degree, this person might define (or refer to) themselves as a chef and when they are cooking, the activity in itself is defining the person as a chef in the world in which he/she interacts. The difference in the previous example is that in the first instance, the person has the objective knowledge to call him or herself a chef, whilst in the second situation the focal activity, i.e., cooking, makes the claim of being a chef apparent. Hence, this explains why Heidegger (1962) makes great emphasis on experiences being perceptual and relative to context. For an exhaustive explanation of Heidegger's (1962) views please refer to *Being and Time*.

Moreover, it seems appropriate to state the way the concept of *lived experience* relates to the previous interpretations of the concept of experience and how it will be used for the purpose of this thesis. Given (2008, p.490) explained that lived experiences are “a representation and understanding of a researcher or research subject’s human experiences, choices, and options and how those factors influence one’s perception of knowledge”. This means that when someone is recalling and/or sharing their lived experiences, the person now shifts their focus on their own self-awareness and previous life experiences (Chaiklin, 1994). Ellis & Flaherty (1992) argued that when an individual is recalling their personal experiences, they are in parallel processing all the subjective and objective factors (e.g., race, gender, place of origin and so forth) in their life, including the physical, political and historical contexts that affected the way they perceived and acted during those experiences. The previous argument paves the way to the concept of sensemaking and how it will be referred to in this thesis. Sensemaking refers to an individual’s “insightful and dynamic descriptions of the relationship between the fore-understanding and the new phenomenon being attended to” (Smith et al., 2009, p.29). For the present study, understanding the participants' sensemaking (also known as making-sense) process, will allow us to appreciate the ways in which people interpret their experiences with technologies and also grasp the reasons for their choices before, during and after adopting the technology (Zamani et al., 2013). This will provide an insight into how ICs make sense of their day to day interactions with ATs for their caring role and bridge the gap between what they originally expected and what actually happened during the experience. This would hence provide a rich understanding of the meaning of ATs for the ICs from this study. Therefore, for the present work, the researcher will not critique the participants' lived experiences but instead, focus on elucidating the sensemaking during their experiences.

2.5.2 Technological adoption and appropriation

This section aims to introduce the concept of technology adoption and appropriation. When exploring the ICs lived experiences with ATs, it is important to have at least a high level understanding of how the participants decided to adopt the technology, what made them accept it and finally how they used it or appropriated it (McCarthy & Wright, 2004). Therefore, it seems fitting at this stage, to state that the purpose of this thesis is not to understand user acceptance and adoption of the technologies under study, but rather to explain through the participants' accounts their lived experiences with technology. Notwithstanding this, the researcher decided to include this section to acknowledge the importance of these concepts as they relate to the study. Therefore, what follows is a brief overview of what these concepts are and how they relate to this investigation.

The concept of technology adoption refers to “the choices an individual makes to accept or reject a particular innovation [technology]” (Straub, 2009, p.626). In other words, this means that technology acceptance is focusing on why people use and/or choose one technology over another. In the same vein, Zamani et al. (2020, p.1) explained that “the success of an IT artefact resides with the user identifying a benefit in information technologies (IT) use against the background of personal use scenarios”. Thus, it makes sense that there is a vast corpus of literature around why users accept technologies and how they adopt it (Barnett et al., 2015). There are various well established theories that aim to explain through models, how technology users accept and adopt technologies. Some of the common questions and discussions within technology adoption theories focus on why people use technology and/or choose to use a particular technology (Recker, 2013). The researcher acknowledges that by incorporating theory to research, relevant factors about technology adoption can be identified and equally provide a foundation and/or emphasis of a person's sensemaking process in regards to their acceptance or rejection of a technology (Aggarwal et al., 2015). The following theory will be mentioned as a way to contextualise and provide a better understanding of the concept of technology adoption, however, this will not be further discussed in this thesis as the subject itself is outside the scope of this investigation.

The Technology Acceptance Model (TAM) by Davis (1989) emphasises two main factors as the underlying influences of a person's acceptance of technology, namely perceived ease of use and perceived usefulness. It is important to understand that the theory says very little about the technology itself, however, what it says a lot about is what people believe or what people perceive a technology to be (Davis, 1989). In other words, whether technology is actually useful or easy to use is not the matter of technology but a matter of peoples' own perceptions that are bound to naturally change. Therefore, depending on how much experience one has, their age and/or gender, the perceptions over a particular piece of technology will change, not because the technology is different but because

people are different. Two limitations were identified for the TAM theory. The first one is that it assumes people plan their behaviour and that they are rational in their actions (Rafique et al., 2020). This means that it assumes that people are actually evaluating the usefulness and ease of use of a technology when we develop an intention to use it and therefore actually use it. The problem with this is that people are not entirely rational in their decision making and not entirely rational in their behaviours either. Hence, not everything that people do is planned or reasoned which the theory does not really account for. For example, when the first iPhone came out, there were people camping in front of the Apple store in order to get a hold of that technology. It was clear at that time that not many people had the chance to actually trial the iPhone prior to that event, which means that most of the people camping had no idea of the actual usefulness or ease of use of that particular iPhone. It was clear that all of the people queuing had an intention to actually buy and get one of these iPhones. Therefore, that thought process cannot be called the reasoned action based on an evaluation of the technology.

A second limitation of the theory is that it does not tell us how to make technology easy to use or useful (Zaineldeen et al., 2020). In other words, it does not provide any advising guidelines to design better technologies other than the general idea provided by Davis (1989) of making sure that technologies are useful and easy to use. It can be argued that most developed technologies initially aim for those two premises, however it is a reality that not all technologies are actually universally useful or easy to use.

Moreover, according to Mendoza et al. (2010, p.5), technology appropriation is “the way that users evaluate and adopt, adapt and integrate a technology into their everyday practices”. In other words, this means that appropriation occurs when a person (or end-user) accepts a technology by adapting it and/or modifying it, to meet their own needs. Zamani et al. (2020) suggested that appropriation is a prerequisite for end-users to continuously use their technologies since they have adapted and incorporated them into their personal lives and routines. The literature suggests that appropriation has at least three main variations, namely improvisations, workarounds and adaptations being the last two, the ones with a vast corpus of research (Zamani et al., 2020). Improvisations are the type of appropriation where the end user is considered innovative and/or intuitive since they have to use whatever is available to them in order to make the technology fit their needs (e.g., using a smartphone to screen films for an older adult) (Ciborra, 1997), workarounds is the type of appropriation where the end-user modifies the structure of the technology and uses it with a purpose other than the original design of that technology (Wibisono et al., 2019) and adaptations refer to when an end-user incorporates the new technology into their day to day activities and routine (Elie-Dit-Cosaque & Straub, 2011).

In the particular case of caregivers, Unbehaun et al. (2020) suggests that technology appropriation normally occurs when the carer “understands what the new technology can be used for and how they can profit from its uses” (p. 520). More specifically, they continue explaining that dementia caregivers commonly attribute meaning to their experiences and therefore they (i.e., carers) use technologies in a certain way to fit their habits and routines.

In a similar vein, Arntzen et al. (2016) identified that “the use and experience of usefulness [in technologies] are highly dependent upon the extent to which the family carers engage, and whether they become interested in the technology and in its potential support” (p.660). Therefore, in order for caregivers to appropriate a technology, they must find the device as a better solution to their day to day activities (e.g. writing a medicine log on paper, or having to be next to the patient 24/7) and a natural fit in their personal lives (e.g., provides them with more personal time) (Arntzen et al., 2016; Unbehaun et al., 2020). The following subsection will explore the concept of postphenomenology. It will also present two frameworks that will help understand how technology mediation occurs within a human-technology relationship and the different dimensions that can be identified during the mediation process.

2.5.3 Human experiences with technology, technology mediation and postphenomenology

Everyday, technology is becoming more and more embedded into everyday life. People are no longer having only one to one experiences (i.e., human to human), but with the boom of technology (more specifically smart devices) it is now common to have experiences with technologies. For example, people are now able to easily capture important moments in their lives with their mobile phones and relive them by watching photos or videos whenever they want to just using their personal phone. It is common practice to also communicate with other people through texts or video calls too. Since human experiences (e.g., subjective, and emotional) are becoming interconnected with technological objects (e.g., objective and instruction driven), a new challenge is being posed for sociologists that aim to understand the interaction between humans, technology and society under a particular context (Kallinikos, 2004). It could be argued that a question is now posed of how is it possible to conceptualise the mediation between humans and technology using social studies without separating the materiality of both entities, one being the creator (i.e., human) and the other one the creation (i.e., technology/artefact).

The literature suggests that a good way to address the dichotomy between the two is through the lens of postphenomenology (Ihde, 1990; Rosenberger and Verbeek, 2015; Langsdorf, 2015; Nizzi, 2015; Aagaard, 2017). Postphenomenology is a contemporary philosophical movement that was created by Don Ihde (1990), with the direct influence of the perspectives of hermeneutics and pragmatism. Ihde

(1990) argued that postphenomenology is concerned with understanding how technologies influence our perception of the world (hermeneutic dimension) and how technology changes what it means to be human (pragmatic dimension). Postphenomenology also focuses on the exploration of the role that technologies play as mediators of everyday experiences (Aagaard, 2017); in other words, how technologies have the capacity to transform our lived experiences. For a thorough understanding of this particular view, please refer to *Postphenomenological Investigations* by Rosenberger and Verbeek (2015).

To understand how technologies transform people's lived experiences, it seems fit to introduce the concept of technological mediation. Technological mediation refers to the indirect relationship technology has between subject (human) and object (world) (Rosenberger and Verbeek, 2015). This concept aims to amplify the mediation role that technologies play in everyday life experiences (Idhe, 1990). Verbeek (2005) explained that when a technology mediates an experience, the artefact becomes the source that directly influences the person's subjective and objective views of their specific situation. In the field of technological mediation, there are four types of human-technology relationships that were identified by Idhe (1990) in his book *Technology and the Lifeworld*. The following are just a description of each relationship (see section 6.4.2 for a discussion of these relationships against the participants' accounts from this thesis):

Embodiment. This relationship is about how technology co-shapes human experience by influencing the person's perception (Idhe, 2008). In this case, technology is to be considered any instrument that becomes an extension of a person's daily life. This instrument can be non-technological (basic tools), such as a spoon, or technological (complex machines and systems, electronics or mechanical tools), such as hearing aids (Idhe, 2009). The main idea is that technology is embodied in the end-user and as a consequence, transforms their experience. Idhe (1990) provided an example of a person who needs prescription glasses to correct their vision. When the person is not wearing their spectacles, the world is blurry. However, when the person wears their glasses, the glasses become an extension of them and their experience is transformed *through* the technology. Idhe (1990) synthesises this relationship as:

(Human-Technology) →World (p.86)

Hermeneutic. In a hermeneutic relationship, the word 'interpretation' is key. This relationship entails the interpretation of textual or visual images through technologies (Idhe, 1995). In this case, a person interprets the world by reading a display on the piece of technology (for example, forming an idea after reading a dashboard). Idhe (1990) illustrated this relationship by reminding

the reader of how people interpret a thermometer. In theory, people read a number from the physical instrument (degrees) and interpret the number into a temperature. This temperature, whether it is to inform the reader about the weather outside or to measure a fever, shapes a person's knowledge about the world, and this is done through technology. Ihde (1990) exhibited this relationship as:

Human →(Technology-World) (p.87)

Alterity. Ihde (2008) explained that the main idea of alterity relationships is that technologies interact directly with a person in a person-like manner (for example, prompting questions). Alterity relationships are purely human-technology relationships, therefore, the world remains in the background. This means that the technology influences the person, but not their world. In alterity relationships, technology imitates the one-to-one interaction between humans. Ihde (1990) illustrated this with an example of a person withdrawing cash from a cash machine. In this case, a person interacts with the cash machine by requesting money and the cash machine responds with precise questions about the transaction (such as whether the person wants to display the balance or print a receipt). According to Ihde (1995), in this type of relationship, the technology remains in the middle because there are certain scenarios in which the technology can briefly interact with the world (such as sending an email), but the world does not interact with the person. This relationship is illustrated by Ihde (1990) as:

Human→Technology(-World) (p.107)

Background. These relationships are the ones in which technology becomes part of the environmental context (Ihde, 1995). In other words, it is when the technology is not focal and does not interact with people, rather, it shapes the perceptions of the experience by remaining in the background. Ihde (1990) exemplified lighting and central heating as having background relationships with people because if they disappeared, experiences would be perceived differently. These are elements that sometimes people take for

granted but significantly contribute to the environment of the experience. Ihde (1990) represented this relationship as:

Human (Technology-World) (p.109)

In table 2.5.3a, a summary of the four presented human-technology mediation relationships. From left to right, the first column displays the type of relationship, followed by the aim and the representation.

Type of human-technology relationship	Aim	Representation
Embodiment relationship	To mediate humans' perceptions of the world through technology	(Human-Technology) → World
Hermeneutic relationship	To mediate humans' perceptions of the world by interpreting a technology	Human → (Technology-World)
Alterity relationship	To relate a human to or with a technology, as opposed to being related to the world via a technology	Human → Technology(-World)
Background relationship	To exist not as a focal, foreground interaction, but in the background of perception	Human (Technology-World)

Table 2.5.3a The types of human-technology mediation (Ihde, 1990)

Moreover, postphenomenology has another interesting framework that is relevant for this work as it focuses on identifying the two-sidedness (that is, the dualities) that delineate technological mediation. The following is an examination of Kiran's (2015) four dimensions of technology mediation. Kiran explained that this two-sidedness refers to how technology mediation intensifies and/or draws our attention to certain actions during an experience, whilst in parallel, blurring or distracting us from other ones. These dualities add an important dimension to the experience of care because it can shed light for designers and developers on the reality of how an AT impacts the life and role of an IC at a personal and societal level. For instance, the dualities could potentially reveal the inability to predict just exactly how the technology will be appropriated and what an experience of care will mean for an IC when it is mediated by these technologies since everything is subject to other factors (for example, the PwD's personality and preferences, the IC's ability with technologies, and so forth).

They could also mean that aspects of care that are challenging (for instance, to prevent wandering) can be balanced by the dualities. For example, to certain ICs when the PwD is very fragile, it is important to have monitoring cameras in the bathroom and in the PwD's room to prevent falls and injuries. To some, this is a breach of the PwD privacy but for others not. Therefore, here the duality could be evaluating if it is ethical or not to monitor, without their consent, all visitors, nurses, and so on that enter those parts of the home. It would be interesting to see if these types of reasoning could provide a middle ground for AT innovation in dementia care that deals with these type of complex challenges (e.g., would designing cameras with face recognition that would only turn on when established users are on the video frame a good solution?). It can be argued that these dimensions can provide the grounds reasoning that designing technologies for dementia care is more complex than expected because people behave differently when technology is mediating the experience (particularly in different cultural contexts). Kiran (2015) stated that the four dimensions are ontological, epistemological, practical, and ethical. Each of these dimensions are described for the present study.

The ontological dimension: revealing-concealing

This first dimension refers to how technology shapes people's worlds (Kiran, 2015). Ontology is the study of understanding the nature of the existing world (Willig, 2013). This dimension refers to how technology has changed people's worldviews (Kiran, 2015). Kiran explained that within this new reality, technology is revealing the world around us, that, in most cases, is new and exciting. It also allows a person to reveal parts of themselves to the world in specific ways. In contrast, this mediated reality is concealing other alternative ways of being in and experiencing the world. For example, social media often reveals the images of ourselves that we want to portray, whilst concealing the truth. This dynamic shapes our identities and how other people perceive us. In the same vein, when searching on social media, you unwittingly reveal your interests to the platform. Henceforth, reality is shaped by your previous searches as the platform targets you with content its algorithms believe you will like. This conceals reality and can shape your opinions and views of the world.

The epistemological dimension: magnification-reduction

Epistemology is concerned with how knowledge is created (Saunders et al., 2011). In this dimension, Kiran (2017) explained that epistemology refers to how a technology shapes people's knowledge. This shaping and creation of knowledge occurs through the process of magnification and reduction. He stated that magnification occurs when a technology augments any of our senses during an experience. In contrast, reduction happens when a technology minimises any of our senses that distract awareness from parts of the experience. For example, having a face- to-face conversation with

someone is experientially different from making a call with a mobile phone. In the first instance, our senses allow us to perceive the other person's level of engagement with the conversation and react appropriately to their expressions. Notwithstanding this, during a phone conversation, a person depends on the technology to start the conversation. In this instance, the telephone magnifies a person's hearing but reduces their other senses.

The practical dimension: enabling-constraining

This dimension refers to the way a technology shapes a person's behaviours and actions (Kiran, 2015). The practical aspect of mediating technologies becomes apparent when they enable a person to perform an activity they desire, however, they constrain the ways the activity can be done (Kiran, 2017). For example, a mobile phone enables communication in real-time with people across the world but constrains the user to establish the desired conversation with certain restrictions: downloading a specific app, having an internet connection, creating an account, having knowledge of how to use the phone, and so on.

The ethical dimension: involving-alienating

The last dimension focuses on emphasising the ethical implications from the previous dimension (practical). The focal point is to categorise the different enabling and constraining behaviours that could raise ethical concerns (Kiran, 2017). Kiran (2015) explained that labelling a technology as 'good' or 'bad' has serious implications. He argued that these labels could involve or alienate a particular technology from people's attention. For example, a fitness tracker could be perceived as a resourceful tool that provides health benefits to a person who is looking to be more conscious about their body parameters. In this way, the fitness tracker is involving in that they give a person an awareness of their own health and habits. However, this technology has been proven to affect people's mental health since fitness trackers encourage people to compete with others by sharing their progress on social media platforms rather than regular one-on-one interactions (Azeemullah, 2019). This constant distraction from reality socially alienates people from their activities and relationships.

Dimension	Description
Ontological	This dimension refers to how technologies have changed people's worldviews.
Epistemological	This dimension refers to how a technology shapes people's knowledge.
Practical	This dimension refers to the way a technology shapes a person's behaviours and actions.
Ethical	The last dimension focuses on emphasising the ethical implications from the previous dimension (practical).

Table 2.5.3b The four dimensions of technological mediation (Kiran, 2015).

2.6 Research on ATs for dementia care

In this section, the researcher aims to discuss the current research on ATs for dementia care. This particularly includes research on the experiences of ICs with ATs since it pertains to this research. In the particular case of ICs (this include formal and informal ones), the literature suggests that technologies can have a significant impact in the way the care is being carried out and perceived (Alasad, 2002; Wikstrom et al., 2007; Price, 2013; Lee, 2004). For instance, Hofhuis et al., (2008) highlighted how the presence of technologies during caregiving duties (e.g., using a surveillance camera) have the potential to distract carers from noticing psychological changes in the care recipient. In the same vein, Price (2013) stated that using technologies for their caring role care can sometimes be perceived by caregivers as impersonal and dehumanising. Finally, Wilkstrom et al. (2007) described that several carers (specifically, formal caregivers) feel safer using technologies to document their actions, objectively, rather than paper-based since it is difficult to follow other formal caregivers' personal notes that are not standardised. They continue arguing that many of the identified errors are associated with human paper-based mistakes (e.g., another formal caregiver illegible handwriting). By understanding what is known about the ATs for ICs is that the basis of this study will be established since it will inform the development of the research design. In section 2.6.1, there will be an exploration of the different research strategies that have been used to evaluate the experiences of ICs of PwDs using ATs. Section 2.6.2 is concentrated on the studies of ATs for dementia care that have been conducted in LMIC. Finally, in section 2.6.3, a holistic picture is provided of the future trends for dementia care technologies and initiatives for a dementia-friendly future.

2.6.1 Previous methods that have been used to evaluate experiences with ATs for dementia care

Researchers of prior studies have stressed the importance of understanding the lived experiences of PwDs and their carers to provide better solutions that could increase their quality of life since there is no known cure for dementia (Brittain et al., 2010; Bartlett, 2014; Gibson et al., 2015). Carmody et al. (2015) suggested that most dementia research is quantitative because funding bodies prioritise this type of research. They argued that there is a paucity of fund grants for qualitative research and as a consequence, many substantial questions are left open relating to people living with a type of dementia and their carers. The Alzheimer's Society (2019) has expressed the need for more qualitative research and the specific need to investigate the experiences of people living with dementia in order to complement the existing quantitative data of previous studies. It has also publicly encouraged funding entities to prioritise the understanding of the experiences of stakeholders within dementia research.

Therefore, in light of the need for qualitative research, this section focuses on examining the different research strategies that have been previously used to study the lived experiences of PwDs and their carers with ATs. The review identified three research strategies in this area of interest, namely, ethnography, grounded theory method, and phenomenology. The examples highlight the way in which each strategy was used and the research questions that they were trying to answer.

Olsson et al. (2013) conducted an *ethnographic approach* (see section 3.3.1) to understand the lived experiences of PwDs and their spouse carers using a passive positioning alarm (for example, a GPS). This type of AT requires the active participation of the carer so that the passive positioning alarm can work properly. This means that the carer needs to activate and place the device inside one of their PwD's pockets. This level of involvement made their perspective very valuable in this exploratory study. Five married couples (one being the carer and the other the PwD) were recruited from an Alzheimer's Disease support centre in Sweden. As part of the study, the researchers provided the AT for the duration of the project. The couples agreed to be observed for a brief period of time in their homes and during outdoor walks (previously planned). Interviews were also conducted jointly after each observation once, and all the subsequent ones conducted separately. Their findings highlighted an increased trust in the technology, even though they described themselves as having poor technological skills. This finding indicated that PwDs and their carers change their perspective towards ATs over time, which emphasises the relevance of ethnographic studies. Olsson et al. (2013) revealed that using this ethnographic approach allowed them to interview the participants in the comfort of their homes, giving them a trusting environment in which they could express themselves freely. It can be argued that some of the strengths of this study are that the authors were able to repeat participant observations and informal conversations (due to the flexibility of participants) and all interactions were done in the comfort of the participants' own homes reducing the challenges of communicating with a PwD. However, an identified weakness was that the spouses who tested the technology were limited to test the monitoring device on their outdoor walks.

Rosenberg and Nygård (2012) aimed to explore the actions of the people that interact with a PwD at home when an AT is used in their daily lives. More specifically, they wanted to understand the dynamics between all the people involved in the care and how the PwD adapts to the AT. The study followed a *grounded theory method* (see section 3.3.1) approach using techniques from a *case study* (see section 3.3.1) approach as well. The main purpose of the study was to understand the influence of technology in the experience. Three families, each with a member affected with a type of dementia, were recruited. The data collection methods were in-depth interviews, observation, and field notes. Each family was treated as one case and analysed following the

guidelines of grounded theory method. Between the three cases, six different types of ATs were identified. It was revealed in the findings of this study that people involved in the PwD's life were driven by doing 'what was right' and therefore, chose the AT for the PwD. The PwD's opinion of the AT was excluded from the final purchase decision. The authors expressed that they considered using grounded theory method for their study as a strength that allowed them to pay close attention to the interactions and details of the experiences, whilst a case study made them give their whole attention to each case rather than aiming for data saturation (as would be the case if only using grounded theory). Notwithstanding this, the authors expressed that an identified weakness to their study was that they only recruited PwD who cohabited with someone else, when it was in their interest to recruit both PwD living alone and with others to have cross case analysis.

Arntzen et al. (2016) explored the implementation process of an AT into the life of a PwD, the meaning of the AT for the PwD, and the role of the family during the adoption period. The recruited participants were a total of 12 PwDs and their respective carers. Each participant was consulted by an occupational therapist that suggested various types of ATs for each case. The suggested ATs were then given to each PwD and carer for a period of 19 months. The study followed a *phenomenological hermeneutical approach* (see section 3.3.1) in which the researchers visited the participants on five occasions (the beginning of the study, and the third, sixth, ninth and twelfth months) to conduct in-depth interviews about their experiences with the AT. It was revealed in their results that the PwD needed to perceive the AT as valuable from an emotional, practical, and relational point of view in order to accept it. Their carers accepted the AT only if they perceived that the device kept their PwD safe and secure. The researchers described how using a phenomenological methodology was a strength of their study since it allowed them to process the very complex process and dynamic that involved the acceptance of the AT. They argued that going beyond the PwD and investigating their family members' interaction with the AT gave them a better understanding of their role as embodied subjects within the experience. A weakness from this study was that the authors used a small sample, making it challenging to generalise their findings to a wider audience.

Evans and Collier (2019) conducted an interpretative phenomenological study (see section 3.3.2) in which they examined the lived experiences of PwD and their carers with a specific AT, namely, electronic calendars. The participants were recruited from support groups in England. A total of six dyads that actively used electronic calendar reminders in their daily lives agreed to participate in the study. The participants were encouraged to take photographs of how they used the calendar reminders. The researchers conducted individual and group (dyad) in-depth interviews, followed by two focus groups with all participants. The collected data were analysed following an

interpretative phenomenological analysis. The researchers found that PwDs felt that this specific AT was used because it was a familiar object and format to them. The main finding of the study was that electronic calendar reminders were used as compensatory aids that facilitated the PwD's independent living and gave reassurance to carers. The authors concluded that their findings supported the idea that ATs for PwDs should be designed to support time orientation. In addition, they argued that their methodological choice was a strength of their work as it allowed them to explore the intangible and implicit parts of the complex experience with a sensitive approach to their vulnerable participants. Nevertheless, an identified weakness was that the study only involved dyads with female carers, hence the views of male carers were not explored. Lastly, the authors also acknowledged that their work was limited by not including the social and cultural contexts of their participants during the analysis.

These four studies presented the different ways in which experiences of ICs with ATs can be explored. It can be argued that each of the different research strategies were chosen by the authors since their research questions and aims subscribed to the epistemology of the selected approach. These studies paved the way for researchers to investigate experiences with technology using a qualitative approach. For example, similarly to Olsson et al. (2013), if the aim of a study is to investigate the outcome of experiences over time, ethnography would be appropriate. In studies where the focus is to explain the experience for social phenomena, adopting grounded theory similarly to Rosenberg and Nygård (2012) would be suitable. Finally, if the aim of a study is to understand the meanings or essence of an experience, as seen in Arntzen et al (2016), a phenomenological approach should be selected. More details about research strategies and the different types will be explored in section 3.3.1. In the next section, previous studies of ATs for dementia care that were conducted in LMIC are presented.

2.6.2 ATs for dementia care in LMICs

This section will present previous studies of ATs in dementia care that have been conducted in LMICs from South Asia and Latin America. Only studies within these two regions were identified and will be discussed since no studies of LMICs with AT solutions specifically for dementia caregivers were found. Therefore, the aim of this section is to document the few studies that were identified addressing the subject of ATs for the field of dementia care exclusively in LMICs and to demonstrate that in those countries, research challenges in the field of ATs for PwD and/or ICs have not been delineated. This section also intends to indirectly hint that there is a need to research and develop AT solutions within this field that will not only benefit a PwD, but also their IC since, in LMICs, it is common that these two stakeholders live together in the same household (Rodriguez Rodriguez, 2013). The following review is not exhaustive, but it provides an overview into research from those countries that focuses on and

explores AT in dementia care. The identified studies were conducted in Pakistan, Bangladesh, India, Ecuador and Mexico. From these studies, only one focuses on ICs that live with their PwD at home, whilst the rest of the studies focus on PwD living independently at home.

Pakistan: According to Asghar et al. (2018) there are no known studies of ATs in dementia care usability in South Asia. In their work, they focus on evaluating the impact of ATs for PwDs since they did not have a reference point of the factors that influenced their acceptance and adoption of these types of technologies. For this study, they adopted a qualitative approach to understand the experiences of PwDs who used ATs on their own for ADL. They conducted surveys and semi-structured interviews with 20 PwDs who used ATs in Pakistan. The data collected was coded using a thematic analysis. Their results revealed that PwDs in Pakistan used ATs mainly for communication, reminders, health, and activity monitoring. Results were also divided since half of their participants perceived the ATs as helpful and beneficial, whilst the other half felt the AT was difficult to use and was making them feel isolated from their family. However, in their findings, the authors suggested that the ATs were, to a certain extent, rehabilitating the PwD since they were being cognitively stimulated on a daily basis. The authors concluded by highlighting the importance of cultural context and how there is an imminent need for tailored ATs for PwDs in Pakistan.

Bangladesh: For the case of Bangladesh, no empirical studies of ATs for dementia care were found. However, Pryor et al. (2018) conducted a study to understand the needs and uses that people with a type of disability have of ATs in two districts of Bangladesh. Even though the authors aimed to assess the different types of ATs within a wide range of disabilities, they found that there was little usage of PwDs – equivalent to 2.7% of the participants. They identified two main reasons for this result: 1) respondents did not know about the existence of any ATs; and 2) they could simply not afford them. Interestingly, their findings suggest that since the participants felt that their needs were unmet, most of them built the ATs themselves from materials that they could find in local markets. For example, they described how some people created their own walking canes by carving wood. The authors concluded their study by highlighting the need for new investments in Bangladesh and suggesting that future work should focus on addressing the gaps of AT need and utilisation.

India: In India, Kasliwal & Patil (2017) designed and developed a real-time monitoring system proof-of-concept for PwD that used GSM and GPS systems to locate them when they wander outside their homes. The system consisted of two communicating artefacts, namely the ICs own mobile phone with the system's app and a wearable device made for the PwD consisting of

miniature tracker. They explained that when the PwD exits the established perimeter, a notification arrives to the ICs mobile phone. This system has only been tested in a laboratory. Another study made in India was from Pirani et al. (2016). They created an android base application called "ALZ" that aimed to assist PwD with diverse functionalities that would increase their independence. For example, the app included food and medicine reminders, their family's information, a GPS and navigation customised to their own home, a panic button and cognitive games. All of the main information has to be configured by their main caregiver. The researcher's conducted surveys, however they did not specify their recruitment process and the synthesis of their results. Therefore, it is unknown the current development of this prototype.

Ecuador: Palacios-Navarro et al. (2015) conducted a pilot study where they developed a virtual reality game for PwD on Microsoft Kinetic, a motion sensing input device. The aim of the game was to motivate PwD to be more active with specific mobility exercises. They recruited seven PwD to test how they received and utilised the virtual reality game for five consecutive weeks in a clinical rehabilitation centre in Ecuador. The participants reported having positive experiences playing with a virtual environment. There were no results presented from the participants' feedback, apart from demographic data. The findings from this study revealed that participants felt safe when testing the game and therefore expressed they would prefer to play this at home, rather than in a clinical setting.

Mexico: Navarro et al. (2016) conducted a two-part pilot study to evaluate a technological intervention using an ambient-assisted intervention system (AaIS) approach. According to their own description, an AaIS is a type of system that aims to improve the quality of life of the PwD by identifying and preventing the presence of challenging behaviour. These types of systems use artificial intelligence to suggest an appropriate intervention or to distract the PwD by modifying something in their environment (for example, loud sounds). The aim of the intervention was to evaluate whether the system was decreasing and managing the problematic behaviours of the PwDs. For the evaluation phase, they recruited two dyads, one who was affected with dementia in Mexico. The implemented system was divided into two components, namely an AnswerPad installed on the ICs' mobile phone (which evaluated the caregiver burden through a survey) and an AnswerBoard implemented on an LCD touchscreen for the PwDs (which displayed cognitive games and medicine reminders). The first part of the study consisted of evaluating first non-technological/traditional interventions (physical puzzles, observing photographs, and so forth) on the participant's home after eight weeks. The second part evaluated the efficacy of the AnswerPad and AnswerBoard after a period of eight weeks as well. The findings of their study suggested that the participants affected with dementia reduced their apathy towards activities and experienced improvements in their overall mood. It was also revealed that their ICs felt less burdened since

the intervention entertained their PwD. They concluded their study by suggesting the need for more data to get a better sense of the efficiency of this system.

In this section, the researcher presented studies from South Asia and Latin America that hinted at the different priorities and diverse projects that exist among nations from the same regions. The first three studies from South Asia suggested that each country has different aims and priorities. For instance, the study conducted in Pakistan was focused on understanding what the factors were for accepting and adopting ATs. In contrast, Bangladesh appears to be far behind, focusing on low-tech AT solutions and exploring the reasons why they have such a low rate of acceptance. It can be argued that Bangladesh might have studies of ATs for PwDs but perhaps they were written in their official language of Bengali. In the last South Asian country, India, an approach was suggested that involved the design and development of an AT that would keep PwDs safe. It can, therefore, be assumed that researchers from India are focusing on developing safety solutions for PwDs.

The two studies presented from Latin America were coincidentally pilot studies of ATs that were used as an intervention. For the case of Ecuador, the aim was to motivate the PwD to increase their mobility with virtual reality and in Mexico, the focus was to decrease the challenging behaviours of a PwD at home through an interactive system that prompted reminders and games. Interestingly, both studies were built around the involvement of the IC of each PwD. With this in mind, it can be argued that researchers from Latin America are looking for solutions that would allow the PwD to live easily with their ICs, rather than to facilitate independence. Perhaps, these trends of research (in India and Latin America) reflect the needs and the priorities set out by the researchers, funding bodies and governments from those countries believe are needed. The next section is a discussion of the potential areas of innovation for ATs in dementia care.

2.6.3 The future of technology in dementia care: the promising directions of emerging technologies

The field of dementia care has been increasingly growing as a result of new technologies that have opened opportunities for innovative solutions (Lindeman et al., 2020). This section will present an overview of the promising new technologies that might direct the future of dementia care research. The review identified four distinctive technology solutions: artificial intelligence (AI) and machine learning (ML), big data and data mining and the Internet of Things (IoT).

AI and ML: Plant (1994) described AI as “the study and implementation of techniques that allow actions requiring intelligence on the part of a human, to be performed on computational devices” (p.1). In other words, it means that computers with AI should have human-like behaviours, for example, robots. In the past decades, the term AI, originally a branch of computer science, has been used in different areas of research (for example, medicine) and combined with ML approaches to innovate in dementia care. According to Joshi (2020), ML refers “to a computer program that can learn to produce a behavior that is not explicitly programmed by the author of the program. Rather is capable of showing behavior that the author may be completely unaware of” (p.4). The combination of AI and ML has proven to have the potential for innovation in dementia research (Ben Miled et al., 2020).

Brayne et al. (2020) suggested that AI has the potential to create technologies that could predict and diagnose dementia in a timely manner. However, they argued that before developing these types of technologies, biased data from clinical records need to be addressed first. They explained that dementia diagnoses have changed and have had different performance effects across the globe in the past decades. In addition, they contend that not having a universal consensus for dementia diagnoses tests as well as unstructured data (for example, medical notes), should be sufficient to attest that the available data is unreliable and potentially biased.

Researchers in several studies focused on using ML techniques to identify dementia promptly. For example, Cleret de Langavant et al. (2018) developed an unsupervised ML classification (an algorithm that created hierarchical clusters) to evaluate the likelihood of a person developing dementia based purely on sociodemographic data from surveys without a professional clinical diagnosis or behavioural measure. The analysed survey was the Survey of Health, Ageing and Retirement in Europe (SHARE). They found that the survey had an accuracy rate of 93.1%, which confirmed its validity. In addition, Lins et al. (2017) created an ML algorithm with the capability to classify nonlinear patterns from a specific database containing the information of PwDs or mild cognitive impairment. The aim of their study was to test the reliability of this algorithm using clinical and psychometric data. Their results suggested that their algorithm had 96.8% accuracy, which is of high relevance to health practitioners since the data analysed were clinical.

Big data and data mining: According to Czarnuch and Astell (2019), big data has no formal definition but it refers to the sizable amount of data that, thanks to technological developments, is easy to collect and store. Notwithstanding this, the authors highlighted the three most important features of big data: volume, velocity, and variety. Within the literature, there are two ways to approach the concept of big data, namely from a qualitative or quantitative lens. For instance,

Baro et al. (2015) developed a definition of big data that addresses the challenges of information veracity that many healthcare related fields face with their quantitative data. Therefore, after a systematic literature review Baro et al. (2015) stated that “big data should exclusively be defined by volume, and a dataset could be qualified as ‘big dataset’ only if is superior or equal to $7 [\log(n * p) \geq 7]$ ” (p.6). A contrasting view is the one offered by Mikalef et al., (2018) who developed a definition of big data with a focus on human skills, knowledge and organisational decision making. Their definition of big data fits into the business context as they view this concept as a way to add business value and competitive performance gains in companies. Through a systematic literature review, Mikalef et al. (2018) demonstrated that big data can be used as a source of competitive business advantage.

Moreover, Hand et al. (2001) described data mining as the area of research that is focused on extracting knowledge and relevant information from huge databases. In dementia research, the common consensus is that big data are datasets from electronic medical records (EMR), magnetic resonance imaging (MRI), positron emission tomography (PET), blood data, cerebrospinal fluid (CSF), and cognitive tests (Deetjen et al., 2015).

Religa et al. (2015) created and evaluated the quality of big datasets from Swedish national database “SveDem”. This database contains all the medical records of people affected with a type of dementia in Sweden from 2007 to the present date. The team of researchers evaluated the quality of clinical reports that were published each year, prior to the creation of the database, to healthcare professionals and policymakers. Their results suggested that using data mining SveDem has the potential for the relevant parties to provide tailored medical treatments and to conduct epidemiological studies, study clinical expressions, and recruit patients for clinical trials.

IoT: The Internet of Things (IoT) is generally defined as a network of systems that communicate and are connected through the internet (Sadoughi et al., 2020). Czarnuch and Astell (2019) suggested that in dementia research, IoT is being used to create full healthcare integrations and smart homes solutions. For example, Rostill et al. (2018) created an integrative system called technology integrated health management (TIHM). TIHM consists of four main elements: 1) the smart devices installed at the patient’s home; 2) the backend of TIHM which includes storage and analysis tools; 3) the user interface; and 4) clinical pathways that will indicate the essential steps that a healthcare practitioner should follow. The aim of this project was to translate raw data from patients with dementia in real-time into useful information and alerts for health providers to provide better care for PwDs. No studies show the level of adoption from this particular project at a grand scale, however the participants who were recruited were aged over 65 and live in Surrey (Rostill et al., 2018). Some of the benefits from this project are that studies show it is possible to deploy

an IoT and machine-learning solution to monitor and manage the health of PwD in the community and that there was a statistically significant reduction in the participants' neurological symptoms, e.g., depression, agitation and anxiety (Rostill et al., 2019). A drawback was identified about this project, being the realisation that TIHM requires improvements in internet connectivity as its signal strength is not consistent across different regions of the country, particularly rural areas where connections are slower (Rostill et al., 2018). The authors implemented their system on the NHS England National Test Bed Programme and concluded that their pilot study was successful and had acceptable results. However, further refinements will be carried out for the second part of their study.

Demir et al. (2017) created a prototype smart home solution that consisted of placing sensors in strategic places in the PwD's home, namely the kitchen, bedroom, bathroom and toilet, that would detect and quantify the activities of daily life of a PwD. More specifically, to monitor actions and prompt reminders if an action is avoided or only partially completed. All the data collected is sent to the cloud and it is analysed in real-time and sent in the form of text notifications or alerts to inform the PwD, their IC and their doctor. The historic data can then be analysed by a doctor to assess the level of dementia progression in the patient. There is no further work about this project since 2017. A strength of this project is that it intends to support PwD independent living by providing a solution that safer environment by identifying activities and their logical consequences in a way that if there is a hazard at home, a reminder is triggered to emergency services and their primary caregiver (Demir et al., 2017). However, a drawback is that the project is not mature enough to discuss and consider the potential scenario of electrical and connection failures (Demir et al., 2017). Therefore, it is still unclear if this smart home solution could be successful and realistic.

There is still a lot to be done before any of these technologies from different emergent areas could be pervasive in our lives. Many aspects need to be considered before any of the aforementioned innovations could be adopted around the globe. For example, ethical concerns, cultural aspects, national resources, health care systems, and technological infrastructures need to be investigated to assess the feasibility of these projects. It can also be argued that in the future, multiple disciplines will have to collaborate with each other in order to address the challenges that each disruptive technology faces and to contribute in the global efforts to overcome this chronic disease. Moreover, designers and developers of dementia technologies will have to consider how these new emerging technologies could be applied to the needs of PwD and their ICs. For example, how with technologies becoming more intelligent they could potentially aid and enhance, in an ethical way, both stakeholders' lives without major disruption (e.g., need to learn the technology or adapt it) during the caregiving experience.

2.6.4 Summary of ATs for dementia care

A review of the current literature in ATs for dementia care was the focal point in this section. A discussion around the different qualitative methodologies that have been used for experiential studies in ATs for dementia care was presented in section 2.6.1. It was stated that the best research strategy would be the one that helps answer the research questions and aims of the study. Section 2.6.2, presented studies that have been conducted in LMICs. The paucity of studies focusing on ATs for dementia care emphasised the need for more research in LMICs. There are a number of potential future technological innovations in dementia care research that were identified in section 2.6.3. These were identified as: AI and ML, big data and data mining, the IoT and autonomous vehicles. A description of each concept and their potential direction in dementia research were stated with examples of studies. The next section provides a synthesis of the literature review.

2.7 Synthesis of the literature review

The evidence provided during this review revealed that the caregiving experience is complex. The involved stakeholders from the caregiving experience, e.g., PwD, IC, siblings, and so on, are affected in different ways, e.g., ambivalent feelings (Losada et al., 2016) and caregiving burden (Wang et al., 2014) and by multiple factors , e.g., family, values, culture, society, and so on (World Health Organization, 2012). Understanding that different complexities existed within their experiences, revealed that the role of informal caregivers is multidimensional (Sander and Power, 2009). This means that ICs are subjected to multiple stressors as part of their many responsibilities (Bertrand et al., 2006; Cuijpers, 2005). A potential limitation of having a multidimensional role, is that some of the affecting factors, namely family, values, society, and so on, will affect stakeholders in different ways and as a consequence their behaviour. For example, in Edgell (2013) it was shown that adult child carers and spouses carers display different caring styles as some factors, such as the relationship to the PwD and values affected their role. The same findings were echoed in Sanders and Power (2009). However, both studies failed to identify specific causes for different behavioural responses among the caregivers who were investigated. This limitation relates to the argument stating that the caregiving experience is complex and thus difficult to comprehend due to all the variable factors that may affect a caregiver. It can be argued that part of the problem within the informal caregiver literature is the misrepresentation of such, since there are few studies that inform us about who they are, what they need and what affects them during their caring experiences (Arevalo-Flechas, 2008; Adams et al., 2002; Mendez-Luck et al., 2008). Therefore, this lack of understanding is a current challenge among the informal caregivers literature that needs to be addressed since this issue not only affects the

advancement in this field but also it affects the provision of solutions within the healthcare system and pertaining governments, such as those from LMICs (Alzheimer's Society, 2017).

Moreover, the review also showed that the state of the art in AT solutions, specifically for ICs, is limited. This was clear when the literature revealed that most of the solutions developed for ICs are technological support interventions rather than solutions to alleviate burden or minimise their responsibilities (Fredericks and Kerns, 2019; O'Connor et al., 2014). When looking at studies what have been used to evaluate experiences with ATs for dementia care, it was also found that none of the studies identified seem to apply, at least in an explicit way in their study, any of the ethical principles from Beauchamp & Childress (1991) and/or discuss any of the common issues within the dementia care literature like, for example stigma (Olsson et al., 2013; Rosenberg and Nygård, 2012; Arntzen et al., 2016; Evan and Collier). A weakness among these studies is that they did not mention or acknowledge the specific conditions that need to be met when doing research with an IT (Stahl, 2012). However, all the previous studies acknowledged and advocated that all studies involving AT and PwD and/or ICs need to have extensive ethical discussions to evaluate the implications for all stakeholders. Therefore, it is clear that there needs to be more studies that support better practices (e.g., ethical designs), in particular for places where culture, society and values are considered highly complex and as a consequence may affect the caregiving experience. It is important to note that all the aforementioned studies are from a clinical perspective, that may not have taken a socio-technical perspective, and therefore there is a need to understand the needs of ATs of carers and PwD from multidisciplinary perspectives, including those from socio-technical perspectives.

Another limitation of AT dementia care solutions is that most of them are designed to help the PwD in their daily lives and not necessarily their ICs (Ienca et al., 2017; Gibson et al., 2016; Beauregard, 2019). However, there are some authors that claim that since the IC has to acquire and operate the AT that will be used for the PwD, then by extension the IC is also benefited by the positive outcomes that come from the PwD utilising and accepting the AT (Stravropoulos et al., 2017; Haritou et al., 2012; How et al., 2013). It is clear then, that a trend within the literature of AT solutions for dementia care is to support the PwD. This argument then strengthens the claim around how misrepresented the informal caregiver is within the literature of AT for dementia care, since even when they are stakeholders of the caregiving experience, the solutions are not directly aimed at their needs.

It was also identified that both the ICs needs and challenges are conditioned by the LMICs in which they reside (Fletcher, 2020). The literature of ATs for dementia care in LMICs revealed two main issues: 1) studies are mainly conducted in South Asia and Latin America; and 2) there is not one single study focusing on a specialised AT for the IC. A limitation to the first point is that having most of the studies from the field of ATs for dementia caregiving from LMICs concentrated in two main regions is disadvantageous as it lacks diversity in the findings and lacks knowledge about the conditions in these

countries which affect the caregiving experience and thus the provision of solutions to their issues. As it has been mentioned in this thesis, the professional care sector is unprepared for the increasing cases of dementia around the world (Zwaanswijk et al., 2013). It has also been stated that evidence suggests that there is a shortage of nursing homes for PwDs in LMICs; therefore, the role of informal caregiving is fundamental, since 95% of PwDs are cared for at home as opposed to in a nursing home (Alzheimer's Disease International, 2019). Without meeting the needs of ICs and providing solutions, their lives will be compromised with an immeasurable amount of stress. The second point aims to emphasise, once again, the issue of misrepresenting the role of an IC and its complexities within the ATs for dementia care literature , which has been echoed in the caregiver literature too. It can be argued that the absence of specialised AT solutions for ICs is potentially a reflection of the lack of funding within the governments of LMICs. It could also be argued that, perhaps solutions are not being proposed because of factors that have not been identified such as stigmas, cultural values, and so on (Fletcher, 2020). However, this is something that has not been explored and that should be of interest to current research, in particular if at one point, the field of AT for dementia caregiving in LMICs aims to create appropriate solutions.

2.8 Gaps in the literature

In this section the researcher concentrates on highlighting the gaps (*in italics*) that have been addressed in this thesis. In short, the focus on this review was on ICs of PwDs (section 2.3), ATs (section 2.4), concepts related to technology mediation (section 2.5), and the current research on ATs of ICs of PwDs (section 2.6). These three elements encompass discrete gaps in the literature. In the following subsections, the researcher takes a wider view of the literature review to establish in a clear manner, the gaps that were addressed for this investigation.

2.8.3 The need to study ICs of PwDs from LMICs.

In section 2.3.1, it was stated that the professional care sector is unprepared for the increasing cases of dementia around the world (Zwaanswijk et al., 2013). Accordingly, the demand and reliance on ICs will increase in LMICs leaving family members with no choice than to care for their PwD at home. It can be argued that since ICs provision of care is unpaid and invisible to many, ICs have become a key stakeholder that helps balance the healthcare and government systems in LMICs. This could mean that if at any point governments face a shortage of ICs, their health and social systems could collapse. *Few studies have been conducted about ICs of PwD from LMICs.*

There was also a discussion around the integral part of the ICs role. It was shown that their roles are multi-dimensional since ICs not only act as carers but they are also advocates and communicators for the PwD. It was also stated that the quality of the care is correlated with the relationship that the IC has with the PwD. This was explored with the example of spouse carers and adult children carers. Both stakeholders had different motivations, strains, and involvement in their care which affected the progression of dementia in the patient. This makes ICs essential players in the quest to fight dementia since they are the people who have daily interactions with PwDs and they provide their care. Nonetheless, there is a gap in the literature about how the factors that influence ICs' provision and perception of care in LMICs. Therefore, there is a *need to understand the complexities that their experiences entail*.

2.8.4 The need to understand how culture influences the caregiving experience in Mexico.

The literature contains different arguments that revealed the importance of understanding culture when investigating caregiving experiences in LMICs. For instance, it was stated that culture shapes the caregiving experience (Aranda & Knight, 1997; Knight & Sayegh, 2010). This means that since culture is a socially constructed concept, there also needs to be a focus in understanding other elements of culture like ethnicity, traditions, ancestry, and so forth. It was shown that these elements increased the prevalence of stigmas, misconceptions and strict religious beliefs around the concept of dementia influence ICs provision of care. Therefore, there is a *need to understand how cultural nuances affect the overall experience of ICs of PwDs from LMICs to develop appropriate support interventions* that could increase dementia awareness and their quality of life.

Moreover, there was a discussion about the impact that already established cultural expectations by family members have on the ICs and the caregiving experience (Napoles et al., 2010; Montgomery, 2014; Scharlach et al., 2006). Accordingly, it was highlighted that there is a *need to investigate family-driven values from specific cultural context to examine the way it influences ICs individually*.

It was then concluded that in the particular case of Mexico, *there is a paucity of research about ICs of PwD*. There is a *need to understand the meanings that Mexican ICs ascribe to dementia so that culturally appropriate interventions can be developed*. There is also a *need to explore the other cultural values that define the Mexican culture and the role that they play in the caregiver experience (other than just familism)*. Finally, in section 2.3.3 it was stated that in the Spanish language there is no word to translate 'caregiver burden' accurately, in the sense the word burden is used in the literature (Arevalo-Flechas, 2008). The closest translation of burden into Spanish is

the word ‘carga’, which in English means load, not an emotional state similarly to how the word burden is used. This theory was only tested in Latino cultures within the USA. Therefore, *there is a gap in the literature of whether Latin American people understand the concept of caregiver burden as it is described in the wide literature.*

2.8.5 The need for knowledge about ATs use in Mexico

The review on ATs highlighted an important point that has not been addressed (thoroughly) in the literature. All the sections from 2.4 provided evidence that types, applications, categorisations, ethical frameworks, and leading studies on ATs have been stated and led by HICs. As a consequence, LMICs can rely only on the research of HICs to create solutions for PwDs (Matter et al., 2017). It can be argued that if LMICs have formed their views around the studies of HICs, then the solutions they have created and will create, are most likely to fail, since these countries have complex cultural contexts. In the same vein, section 2.5.2 indicated that all of the top 10 countries leading the research of ATs in dementia care were HICs. Hence, *the need for exploratory studies that could elucidate the complexities that exist in LMICs to create appropriate AT solutions.*

It was also stated that only one pilot study was identified in Mexico that explored technologies for dementia care (Navarro et al., 2016). Notwithstanding this, the technology discussed was not an AT but an AaIS. Thus, *there is a need to investigate ATs in Mexico and other technologies that could benefit dementia care research.* In this study, the researcher addresses this specific gap by exploring the types of ATs that are being used for dementia care, the motivations for use, the way they appropriate the technology and the meanings they ascribe to the AT.

2.9 Conclusion

Chapter 2 presented the literature review and the identified gaps that this research intend to fill. It provided a holistic understanding of what comprises the role of ICs, the challenges that they face and the different types of support interventions that currently exist. The chapter also provided the main applications and categorisations for ATs in dementia care. A comprehensive discussion about the ethical considerations that dementia technologies need to address was also explored. The current state of the literature in ATs for dementia care was presented. Finally, the gaps found in the literature were established. The next chapter (Chapter 3: Methodology) aims to examine the methodology and methods that were selected for this investigation.

Chapter 3: Methodology

3.1 Introduction

In Chapter 2, Literature Review, there was an exploration of the literature of informal caregivers (ICs) of a person with dementia (PwD) (section 2.3) and assistive technologies (ATs) for dementia (section 2.4). The review established the gaps that this study intends to bridge (section 2.7). Chapter 3, Methodology, presents an overview of the methodology and data collection methods used in this investigation. This chapter is divided into the following sections: Section 3.2 Research Philosophy, introduces the researcher's philosophical stance and discusses the selected research paradigm and research approach. Section 3.3 Research Strategy, describes the selected methodology and alternative approaches considered. Section 3.4 Research Design, provides the details of how the research was conducted and analysed. Section 3.5 Ethical considerations, details all the procedures followed to ensure participants dignity, confidentiality and security during the investigation. Section 3.6 Reflexivity, provides the purpose of this exercise and its role within the research. Section 3.7 Conclusion, closes the chapter with a comprehensive synthesis. With the aforementioned sections in mind, this chapter guides the discussion of the different options that were explored and identified by the researcher and how the selected methodology helped answer this project's research question:

How do Mexican informal caregivers of people with dementia make sense and experience their use of assistive technologies to aid their role?

3.2 Research Philosophy

This section discusses the philosophical stance and theoretical perspectives adopted for this investigation. Easterby-Smith et al. (2012) suggested that a consideration of the philosophical basis of an inquiry is beneficial to research because it guides the selection of a research strategy and methods. It also helps the researcher to identify the limitations of different approaches, thus avoiding unnecessary work. This also opens the door to methodological innovation, which can lead to better research. The term "research philosophy" involves understanding that research is about the "development of knowledge and the nature of that knowledge" (Saunders et al., 2011, p. 107). In other words, it concerns the creation of new knowledge in a particular field through reflecting on already established philosophical views. The nature of that knowledge explains the researcher's perspective and helps them choose methods and strategies that enable them to answer their research questions. Furthermore, it focuses on stating the assumptions and

worldviews of a researcher (Smith, 1998). Thus, the philosophical stance of the researcher at the outset of their project dictates the way the phenomenon or problem is observed and analysed (Bryman, 2012). It is fundamental to state the philosophical assumptions that, taken together, will create a holistic view of how the researcher views and develops this knowledge.

3.2.1 Research Purpose

Defining the purpose of the research is crucial in the initial stages of the study in order to understand how the study will be conducted and analysed. According to Saunders et al. (2011), research purposes can be explanatory, exploratory or descriptive. Explanatory studies are those that focus on explaining a causality or difference by creating an initial hypothesis or by testing an existing theory to understand the relationships among the involved entities. If a problem or phenomenon has not been the subject of much research, an exploratory study enables a researcher to understand how the problem or phenomenon happened or why it started. Descriptive research aims to detail the subject or phenomena under investigation in an accurate way. The intention of this investigation was to examine the lived experience of ICs of PwD using ATs for their caring role in a developing country, namely Mexico. The purpose of the present research is exploratory because this subject has not been studied before in a developing country, nor less Mexico.

3.2.2 Philosophical assumptions

This section explores ontology and epistemology as the two main assumptions of social science research, as well as the stance of this research for each one respectively (Bryman, 2012). It is important to understand the main philosophical assumptions in social sciences, to answer the research question, as they describe the researcher's worldview and his/her stance in relation to this worldview (Saunders et al., 2011).

Ontology. Ontology is the study of being concerned with knowing the nature of the existing world and is focused on seeking answers to 'what is reality?' and 'what exists?' (Willig, 2013; Bryman, 2012; Gray, 2013). Willig (2013) suggests that every researcher has previous assumptions about the world and these ontological realities define the researcher's relationship to the study. This means that the ontological position will define whether the researcher is independent of, or participatory in, the construction of knowledge (Bryman, 2012). There are two dominant positions in ontology: *realist* and *relativist* (Willig, 2013).

Realist. Killam (2013) suggested that, as the name implies, realists are driven by the belief that there is one unique reality and truth, which is objective. This truth is governed by static natural laws, can be measured with experiments and is independent of human subjectivity. Realists also believe

that any study involving people can be analysed systematically in their natural context because participants act independently from the spectator (Gray, 2013). Realism is an ontological perspective used when adopting a post-positivist paradigm of research.

Relativist. Relativists, in contrast, build their reality based on individual experiences where “truth of x is relative to the truth of y” (Zimmerman, 2007, p. 314). They recognise a phenomenon as inter-subjective, based on content and knowledge on the social and empirical levels (Willig, 2013). Blaikie (2007) suggested that relativism supposes that reality only exists in our minds as it is being constructed by thoughts and does not occur autonomously from our perception. Relativists, from an ontological point of view, are concerned with contextual factors in the world (for example social, political, historical, and so forth) and the diverse intertwined relationships that can be interpreted from different angles (Willig, 2013). Due to its subjective nature, relativism is generally used when adopting a constructivist paradigm of research.

Epistemology. The concerns of epistemological philosophical assumptions are about how knowledge is created (Saunders et al., 2011). It aims to understand the theory, justification and the kinds of knowledge that are legitimate and adequate for obtaining the truth (Bryman, 2012). This assumption reflects the researcher’s relationship and position towards the investigation, which is the driving force for choosing the methodology (Saunders et al., 2011). The two main epistemological assumptions in social science research are positivism and interpretivism (Bryman, 2012).

Positivism. The belief of positivism is that credible data can be obtained through direct observation and measurement of a natural phenomenon that can form a universal truth (Guba, 1990). The role of the researcher is limited to only the collection of data and interpretation of the measurable results whilst holding an objective attitude (Saunders et al., 2011). Additionally, positivists focus on statistical analysis to generate facts that will explain and model a specific phenomenon (Walliman, 2011). These arguments appoint science as the foundation of positivism. It is fundamental that the researcher maintains distance from the research to prevent any influences on the results, as social knowledge exists in itself (Thietart, 2001).

Interpretivism. The contrasting assumption to positivism is interpretivism. This theoretical perspective assumes “that access to reality (given or socially constructed) is only through social constructions such as language, consciousness, shared meanings, and instruments” (Myers, 2013, p. 39). Its proponents also claim that human behaviour is complex, and thus impossible to measure using scientific methods (Gray, 2013). This demonstrates that interpretivism is subjective as there

is a lack of empirical evidence and the researcher is required to interact with the participant's setting to understand their viewpoints. Furthermore, its aim is to unravel the underlying meanings that participants assign to people, places and things around them and that are pertaining to the phenomena under study (Boland, 1991). Interpretivism can be approached in different ways (Gray, 2013). These variations help refine the view that is adopted in the research (Creswell, 2007). The two most common interpretative approaches for experiential research are *phenomenology* and *hermeneutics* (Aagaard, 2017b).

Phenomenology. Phenomenology was influenced by the philosophical perspective of Edmund Husserl, and other philosophers who have introduced variations in phenomenological research, for example, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2009). Morse (1991) described phenomenological research as being "a human science that strives to 'interpret and understand' rather than to 'observe and explain', which is an approach normally found in a natural science" (p.59). In other words, researchers using this approach seek to discover the essence, underlying meaning and essentials of human experience by removing any preconceptions from their lives, and use intuition and creativity to comprehend the participant's reality (Miller & Salkind, 2002). Furthermore, it focuses on developing an understanding through an inductive logic, the participant's subjective experience, interpretations, and opinions about the phenomenon under study (Gray, 2013).

Hermeneutics. Hermeneutics is the branch that deals with the theory of interpretation and was used to interpret sacred texts, historical documents, and poetry (Smith et al., 2009). It focuses on the role that language plays in the world and in experiences (Moran & Mooney, 2002). Hermeneutics has been directly influenced by phenomenology as it is also concerned with interpreting meaning (Aagaard, 2017b). Martin Heidegger was an influential hermeneutic philosopher who agreed with phenomenology because it supported his idea that meaning was hidden between texts and interpretation was a way to disclose them (Smith et al., 2009). As a result of his views, the hermeneutic-phenomenology perspective, which derives from interpretivism, was formed (Gray, 2013).

Table 3.2.2 shows the ontological and epistemological positions in relation to the research paradigms that will be described in section 3.2.3.

Characteristic	Post-positivist	Constructivist	Participatory Inquiry	Pragmatism
Ontology	Realist	Relativist	Realist	Relativist
Epistemology	Positivism	Interpretivism	Interpretivism	Combination of both
Role of the Researcher	Objective, observer	Subjective, interacts with participants	Subjective	Goal oriented

Table 3.2.2. Summary of philosophical assumptions.

The epistemological position of *interpretivism* and the ontological view of *relativism* were selected for this research. The research questions of this study are grounded in the epistemological position of interpretivism as they focus on exploring the experiential connection that Mexican ICs develop with ATs and how they make sense of ATs mediating their experience. The theoretical focus of *hermeneutical phenomenology* was adopted to facilitate the elicitation of the hidden meanings inside the transcripts of the participants' interviews. Mexico is a country that is culturally rich, with specific values and traditions. The ontological view of relativism was selected, because it acknowledges that the aforementioned elements directly influence a participant's construction of reality. Relativism focuses on subjective experiences and is relevant to complex relationships around ICs, which will allow for an in-depth and truthful elicitation of the participants' first-person accounts.

3.2.3 Research Paradigm

In the social sciences, there is not a unanimous definition for the term “research paradigm” nor a defined set of universal paradigms for researchers to use (Guba, 1990). This is because each author has different experiences that influence how research paradigms are chosen and defined (Bryman, 2012; Burrell & Morgan, 1979; Guba & Lincoln, 1979). Some authors oppose the use of the term “paradigm” altogether (Hammersley, 1992). This investigation adopted the definition of a research paradigm as “the basic belief system or worldview that guides the investigator, not only in choices of a method but in ontologically [see Section 3.2.2] and epistemologically [see Section 3.2.2] fundamental ways” (Guba & Lincoln, 1994, p. 105). In simple terms, this is the lens through which the world is seen and which shapes how a problem is approached. When adopting a research paradigm in the social sciences, the researcher is not aiming to establish an absolute truth or new discovery, but to justify and clarify how they approached their research based on their beliefs and/or worldviews (Guba, 1990).

Authors such as Burrell & Morgan (1979), Orlowski & Baroudi (1991), Guba & Lincoln (1994) and Creswell (2013) differ in their typologies of research paradigms. Guba & Lincoln (1994), for example, outlined four types: positivism, post-positivism, constructivism and critical theory. In contrast, Bryman (2012) argued that positivism and interpretivism are the only research paradigm typologies. For this study, Creswell's (2013) four research paradigms were used, since they allowed the researcher to explain in detail how this study was viewed and rationalised. Notwithstanding this, other authors who concur with some of Creswell's paradigms will be included to complement the discussion. The four paradigms are *constructivism*, *post-positivism*, *participatory inquiry*, and *pragmatism*.

Constructivism. Guba (1990, p. 26) suggested that constructivism "depicts knowledge as the outcome or consequence of human activity; knowledge is a human construction, never certifiable as ultimately true but problematic and ever-changing". He explained that constructivists consider the positivists' view of the world (described in Section 3.2.2) as flawed for stating that there is only one truth. In contrast, constructivists believe many realities can be constructed from people's minds and can only be interpreted from a subjective perspective (Gray, 2013). This suggests that knowledge is co-constructed as a result of the researcher's subjective interaction with participants in their natural environment, and that it can have many meanings that vary from person to person over time and depending on purpose. Thus, knowledge is constructed by giving meaning to the participant's social and cultural context, relationships, and community interactions. This is accomplished with the help of qualitative methods due to their subjective nature. Examples of these are interviews and participant observation, among others (Young & Collin, 2004).

Post-positivism. Post-positivism aims to obtain knowledge through prediction, observation and control with an objective perspective (Guba, 1990). Onwuegbuzie et al. (2011) suggested that post-positivists can only perceive pieces of reality because observations are fallible due to the subjectivity of human reactions under diverse circumstances and, thus, they can only approximate to reality and truth. In a more comprehensive way, through observation and measurement, probabilities can be assigned to make inferential statistics that transform into knowledge. Therefore, there is not an absolute truth under this view, only probabilities (Creswell, 2007). Both qualitative and quantitative methods can be used within this paradigm (Pickard, 2012).

Participatory inquiry. Gray (2013, p. 23) defined participatory inquiry as a paradigm that “questions currently held values and assumptions and challenges conventional social structures”. Nonetheless, the main distinction between this paradigm and the others is that reality is influenced by the oppressive experiences that participants undergo in a society. This presents as an invitation for the researcher to question current social structures and values, instead of focusing only on interpreting the world (Gray, 2013). As realities are socially constructed, they will always be influenced by an internal power source such as a feminist or materialist way of thinking (Guba, 1990). The aim of the participatory paradigm research is not only the acquisition of knowledge, but there is also a focus on actions by empowering their participants to implement change in their communities (Heron & Reason, 1997). Qualitative and quantitative methods can be used in this particular paradigm for the collection and analysis of data (Willmott, 2008).

Pragmatism. Pragmatists believe that reality is debatable and modifiable as it is subject to different interpretations and, because of this, the truth can be discovered with any method as long as it is beneficial for answering the research question (Saunders et al., 2011). A particular philosophical stance is not adopted in this approach (Creswell, 2007). Moreover, it is pluralistic as the use of many methods from other paradigms is allowed (Johnson & Onwuegbuzie, 2004). Hence, depending on the research questions, either quantitative and/or qualitative methods can be used within this paradigm (Tashakkori & Teddlie, 1998). Table 3.2.3 presents a summary of the key points of the four research paradigms discussed in this section that are used in social science research.

	Constructivism	Post-Positivism	Participatory Inquiry	Pragmatism
View	Not one truth	One truth and probabilities	Political structures	Changeable and constantly renegotiated
Belief	Many realities	One reality	Transformative social change	Facilitate human problem-solving
Perspective	Subjective	Objective	Subjective	Subjective and/or Objective
Constructs knowledge	Co-constructed from people's minds	Through prediction, observation and control.	Through the political beliefs and opinions of the researcher	Based on experience.

Table 3.2.3 Summary of research paradigms for social sciences.

On account of the above considerations, the selected paradigm for this research is constructivism. The reason behind this choice is because constructivism is compatible with the previous selected views of relativism and interpretivism. Constructivism will allow the researcher to create multiple assumptions as data is interpreted. Since each participant situation is unique, there is not an absolute truth, thus meaning has to be constructed as interactions occur.

3.2.4 Research Approach

The aim of this section is to explore two different ways in which research can be approached: inductively or deductively. As theory and research are, by nature, interrelated, it is important to define the way theory is rationalised in a study (Bryman, 2012). The theory is tested or created throughout an investigation, defining the role it plays in guiding and influencing the method of research (Saunders et al., 2011).

Through empirical analysis, researchers using the *deductive approach* test a theory or hypothesis to be true or false (Bryman, 2012). The deductive approach logic implies that, if while testing the theories or hypotheses the premises are true, then the conclusions ought to be true too (Gray, 2013). Saunders et al. (2011) suggested that existing theories can be found within the literature and once they have been selected, the researcher can start testing them, possibly revise them, and/or refute them. This is known as the ‘top-down approach’, in which the researcher starts working from the general, being the top, to the specific, being the bottom (Myers, 2013).

The *inductive approach* is the converse of the deductive approach. The inductive aims to explore empirical data through a ‘bottom-up approach’ (specifics to general) to establish patterns, coherence, and purpose (Myers, 2013). Its objective is to generate meanings or, in some cases, theories from gathered data, which are compared to the literature afterwards (Saunders et al., 2011). It is not expected that the researcher has to know all the literature in order to use the inductive approach; on the contrary, a comprehensive review of the most relevant literature in the field and the researcher’s pre-existing judgements should be sufficient for formulating the research questions (Saunders et al., 2011).

Consistent with the selected philosophical views from the previous sections and taking into consideration the subjective nature of this research, it was decided that an inductive approach would be followed. The aim of this study was to interpret the meanings embedded within the relationships of ICs and ATs as a consequence of their caregiving experiences. The intention was also to investigate the ways ATs were used, the motivation to get the technology, how the ICs accepted the AT and whether appropriation occurred. The purpose of this research was exploratory. Therefore, the intention of obtaining the findings was to inform and suggest further exploration into relevant theories from the field of information systems. This means that an

inductive approach was suitable for this investigation.

3.3 Research Strategy

Having described the research philosophy adopted for this study in Section 3.2, the aim of this section is to provide a description of the difference between qualitative and quantitative methods and present an in-depth exploration of the selected research strategy and the alternative approaches considered for this investigation.

A quantitative approach “is deductivist and objectivist and incorporates a natural science model of the research process (in particular, one influenced by positivism)” (Bryman, 2012, p. 715). Additionally, its aim is to test human behaviour through theory and concepts in an artificial setting by quantifying and analysing samples that will generalise findings in a structured way (Bryman, 2012). Flick (2015) suggested that in this type of approach, the worldview is fixed and the researchers are uninvolved with the participants, meaning that the subjects’ points of view are irrelevant. This research approach was not utilised in this study as the underpinning philosophical assumptions were not compatible with the research, so there will not be an exploration into the different strategies within this category.

Those taking a qualitative approach are “interested in how people make sense of the world and how they experience events” (Willig, 2013, p. 8). The main objective is that, through an inductive approach and an interpretivist assumption, the investigator creates theory without claiming an absolute truth (Bryman, 2012). Saunders et al. (2011) suggested that it is an unstructured process in which the researcher comprehends the phenomenon by immersing themselves in it, so that theory and concepts can be developed from data and be transformed into meaningful patterns.

For the purpose of this investigation, a qualitative approach was selected as it aligned with the aims and objectives of the study and it allowed the researcher to elicit detailed first-person experiential accounts of the participants under investigation. This approach facilitated the exploration of this phenomenon and permitted the researcher to interact with the participants in a guided and controlled manner. In addition, qualitative research made sense, since it works harmoniously with the stated philosophical views from previous sections and it can purposefully be adjusted to the subjective and interpretative nature of this investigation.

Table 3.3, below is a summary of the selected philosophical choices and methodological approaches for this research.

Research Paradigm	Constructivism
Ontology	Relativist
Epistemology	Interpretivism -Phenomenology -Hermeneutics
Research Approach	Inductive approach
Research Strategy	Qualitative approach

Table 3.3 Summary of the researcher's philosophical stance.

Kaplan (1973) defined the purpose of research strategy as "to describe and analyse methods, throwing light on their limitations and resources, clarifying their suppositions and consequences, relating their potentialities to the twilight zone at the frontiers of knowledge" (p. 23). In simple terms, research strategy refers to selecting, planning, assessing, and explaining the methods one chooses for their study (Bryman, 2012). Saunders et al. (2011) suggested that there are several factors that have a significant influence in the selection of a research strategy, such as the researcher's prior knowledge of the subject, the philosophical assumptions, the nature of the research questions, the length of the project and the project's aim. Willig (2013) also suggested that, from these factors, the philosophical assumption of epistemology is considered to be the most influential in guiding the nature of the strategy since it constrains which methods to use in the study. She extended this statement by explaining that not all methods are appropriate for some research strategies, because they are not always compatible. An example of this is using qualitative methods, such as an interview (see section 3.4.1.2), to measure variables within a sample or population. This contradicts the purpose of an interpretivist assumption (as described in section 3.2.2), which is the driving force in a qualitative research strategy (Willig, 2013).

3.3.1 Alternative Approaches Considered

In this section, there is an introduction to the research strategies that were also considered for this qualitative study. As this study involved participants who were considered vulnerable, only qualitative research strategies from the information science realm that allowed the researcher to investigate in an ethical, experiential, and empathetic manner were considered. The considered research strategies were grounded theory, ethnography, case studies, narrative analysis and phenomenological research. Each subsection contains a brief discussion and an outline of the researcher's reasons for choosing the specific research strategy.

Grounded Theory Method (GTM) was developed by Glaser and Strauss in 1967, who objected to how existing theories dictate social research. GTM is a way “to identify and explicate contextualized social processes” (Willig, 2013, p.47). They described the method as “theory that was derived from data, systematically gathered and analysed through the research process” (Strauss & Corbin, 1998, p.12). Flick (2015) explained that grounded theory does not use theoretical assumptions, rather its aim is to construct a contextualised theory out of the gathered data. It is clear from the two aforesaid descriptions that this strategy contains a description of one of the main characteristics of a qualitative approach, which is generating new theories through induction, rather than testing them (Willig, 2013). Wiesche et al. (2017, p.686) elucidated that “the method is particularly relevant for research on issues for which limited prior research has been conducted and for which theory building is needed”. They further explained that although developing theory is an espoused goal of GTM, in some cases, developing models and/or formulating richer descriptions of new phenomena could be an alternative way to approach GTM. These three different types of research contributions can be differentiating in what follows.

Theories are the type of contributions that include relevant variables and an explication of the relationship between those variables (Whetten, 1989). Moreover, it also includes the justifications of the relationships of the variables and the limits of the theory (Whetten, 1989). Models contain the definitions of any relevant variables and the relationships among them, however, they do not aim to justify the relationships nor limit their boundaries (Markus and Robey, 1988). Lastly, rich descriptions of phenomena are “narratives based on empirical observations without abstraction” (Wiesche et al., 2017, p.686).

GTM has an appropriate selection of suitable techniques for data collection, including various types of interviews, participant observation, and diaries (Willig, 2013). There are also predetermined sets of tools and/or procedures that provide guidance whilst the researcher analyses the data, for example, theoretical sampling, coding, theoretical saturation, and constant comparison (Bryman,

2012). The aim of the analysis is to ground theory in data by creating concepts and categories (Willig, 2013). The researcher cannot bring their own assumptions or expectations when analysing and interpreting the data.

GTM has been used across different disciplines and for multiple types of studies, including experiential research (Smith et al., 2009). Notwithstanding this, even when the focus of GTM is on experiential research, the aim is still to create a conceptual explanation of the participants' accounts to illustrate the resultant theoretical claim or to challenge theories (Boyd & Gumley, 2007; Cutcliffe, 2000; Tweed & Charmaz, 2012). Therefore, this approach was not selected since this study aimed to create first-person accounts.. Furthermore, the vulnerability of the participants, the cultural context and the difficulty in finding a sample experiencing the phenomena under investigation were crucial factors in the exclusion of this strategy.

Bryman (2012) defined *ethnography* as “a research method in which the researcher immerses him or herself in a social setting for an extended period of time, observing behaviour, listening to what is said in conversations both between others and with the fieldworker, and asking questions” (p. 711). This definition indicates that ethnography is a method in which the researcher has to actively participate every day in people's lives by getting to know them as intimately as if the researcher is part of their culture (Flick, 2015). In addition, the aim of this methodology is to identify the link between culture and people's reactions to a particular event or phenomenon (Gray, 2013). Therefore, it is recommended that when adopting this methodology, the researcher considers living in a place close to the participants to be able to start conversations with them and understand their environment (Bryman, 2012). Some of the frequently used data gathering methods are observations, interviews, field notes, and the collecting of documents (Bryman, 2012; Gray, 2013). Data analysis uses interpretative methods that will help give meaning to any established behaviour or statement given by a participant (Flick, 2015). Gray (2013) also suggested that this research method does not have a defined or recommended number of participants required for the study; it can be as many as needed. Finally, ethnography attains reliability of data through triangulation, that is, having various sources of data collection that can be cross-checked (Gray, 2013). Ethnography is an exploratory method that focuses on a culture, requiring interaction with participants in a specific location to understand the meanings created through their narratives (Maggs-Rapport, 2000). It requires a profound understanding of the participants' views, values, behaviours and language to describe the knowledge they construct through culture (Flick, 2015).

This is an exploratory study, the aim of which is to uncover the essence of the relationship that is formed by ICs with ATs during their caring role and the way in which ATs shape ICs' perception

of the phenomenon. Ethnography facilitates the interaction with participants from different cultures in an emphatic and ethical way (Gray, 2013). However, the required length of time for extended observation was not suitable given that the funds for the research were limited and PwD may show any common dementia symptoms, including aggression, which could be harmful during interviews with ICs (Fauth & Gibbons, 2014). From an ethical point of view, it would have been difficult to overcome all of the possible constraints that such a sensitive topic could be subject to. Thus, it was decided that ethnography would not be used in this research.

Case studies focus on an exhaustive analysis and exploration of a single case (or several cases) that can be an institution, situation, incident or even experience (Bryman, 2012; Willig, 2013). Case studies allow a single complex situation to be analysed from different angles with the help of different resources, to better understand the phenomena in place (Baxter & Jack, 2008). Willig (2013) defined a case as “the particular unit of analysis” (p. 74). Cases are analysed to answer the ‘hows and whys’ of complicated human experiences (Yin, 2009). This approach uses the following methods for data collection: interviews, focus groups, observations, surveys or paper-based notes that could help the researcher to better understand the story each participant has to tell of the phenomenon under study (Crabtree & Miller, 1999). Willig (2013) described several characteristic features of case studies, such as their focus on the specific details, rather than the general, and that they follow a holistic approach as the overall framework of the case is examined. She explained that case studies occur within a specific period of time, so it is important to understand that change and development can occur throughout the project. Yin (2009) highlighted that case studies begin with the formulation of a hypothesis or theory that will guide the entire investigation. He outlined five types of case studies: critical, unique, representative, revelatory, and longitudinal. He also stated that case studies could contain a combination of the aforementioned types. This research strategy is suitable for qualitative and quantitative methods (Bryman, 2012). Case studies allow in-depth descriptions of cases bounded in experiences (namely, ICs of PwD) to be provided, taking into account participants’ feelings, beliefs, and the cultural context (Gray, 2013). Nonetheless, they are limited to descriptions and do not focus on sense-making and essence (Willig, 2013). Hence, case studies were not compatible with the researcher’s philosophical views and, as a consequence, were deemed not suitable for this research.

Phenomenological research is rooted in the philosophical views of phenomenology (Creswell, 2007). This type of research strategy allows researchers to understand the world in terms of the relations that humans form using intentionality (Verbeek, 2005). Intentionality “is the power of minds and mental states to be about, to represent, or to stand for, things, properties and states of affairs” (Jacob, 2019, p. 1). This means that this concept is a very basic form of human intuition because, for example, we cannot just hear, we always hear something and somehow we always direct this attribution at the world around us. Hence, phenomenology tries to take intentionality as a starting point for everyday experience. From the traditional phenomenological research perspective, consciousness is key, as it contains the participants’ experiences from the past and present that provide meanings, images and memories that are fundamental for extracting knowledge (Miller & Salkind, 2002). When using this research strategy, data is gathered using unstructured methods, for example, in-depth interviews and narratives, since they provide accurate descriptions of the experience (Gray, 2013). Other less frequently used data collection methods are diaries and visual methods (Bloor & Wood, 2006). As part of the analysis, phenomenological researchers use reduction (techniques to extract essence), the creation of themes and the construction of meanings (Miller & Salkind, 2002). Samples tend to contain between five and ten participants and the two most common sampling strategies are purposive and systematic (Bloor & Wood, 2006). Phenomenology has many variants that permit researchers to adopt a perspective that fits comfortably with their views or to answer specific questions that relate to human experiences and meaning (Creswell, 2007). Notwithstanding this, the following two phenomenological approaches can be used for experiential research: descriptive and hermeneutic (Aagaard, 2017b).

The *descriptive* type was introduced by Husserl, the father of phenomenology, and the focus of this is on understanding and giving meaning to particular human experiences (Miller & Salkind, 2002). This approach aims to bracket any previous memories, knowledge, judgements, or experiences, to avoid any imposition from the researcher that could taint the data (Crotty, 1998). Willig (2013) explained that descriptive phenomenological research has a degree of dependency on the researcher’s intuition and creativity to comprehend the worldview from the participants, since the analysis is subjective. In short, the premise of this type of approach is that presuppositions from the researcher may cloud the purity of human experience, so that the focus should be on deciphering the perception of the participants (Smith et al., 2009). This is accomplished through a series of already established procedures that will help statements extracted from interviews to be analysed and used to later on form themes (Crotty, 1998).

In contrast to descriptive phenomenology, the *hermeneutic* approach uses previous assumptions and knowledge from the researcher's worldview to better understand the perception of participants experiencing phenomena in a particular context (Willig, 2013). This branch of phenomenology was first introduced by the philosophical scholar Heidegger (Lopez & Willis, 2004). Miller & Salkind (2002) suggested that this approach, which is rooted in interpretation, focuses on the connection between an experience and a participant, and how knowledge is constructed from that exchange. To produce a hermeneutic interpretation, an iterative process called the hermeneutic circle is implemented by the researcher to facilitate the understanding of texts (Moustakas, 1994). Smith et al. (2009) suggested that the hermeneutic circle works with 'parts' and 'wholes' because "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (p. 28). The connotation of words, which are the parts, becomes clear when seen through the whole context. Willig (2013) explained that the hermeneutic circle uses the researcher's presuppositions and tests them while analysing narratives so that every emerging set of meanings or themes can advance the understanding of the phenomena under study. Hermeneutic phenomenology is concerned with engaging with the participants' narratives and interpreting their beliefs and way of thinking in relation to the events under study (Willig, 2013). Finally, this approach does not have a unique truth; it can have several interpretations, due to the many ways that phenomena can be perceived (Miller & Salkind, 2002).

3.3.2 Interpretative Phenomenological Analysis

This section contains an in-depth exploration of the selected methodology called interpretative phenomenological analysis (IPA) and introduces the procedures it is comprised of. Discussion of the rationale for this choice and the application of IPA to this research are included in this section.

IPA is a variation of hermeneutic phenomenological research, founded by Jonathan Smith and popularised in the mid-1990s in the field of psychology (Smith, 1996). Nowadays it is used in the research of diverse areas, such as healthcare, education and nursing (Roberts, 2013). Pietkiewicz & Smith (2012) define IPA as "a dynamic process with an active role of the researcher which will influence the extent to which they get access to the participant's experience and how, through interpretative activity, they will make sense of the subject's personal world" (p.362). Smith & Osborn (2008) described the aim of IPA as follows: "to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants" (p.53). The last two definitions support the idea that every IPA researcher should attempt to walk in the participant's shoes throughout the study and to understand them as much as possible in order to truly reflect the participant's perceptions with the process of interpretation (Willig, 2013). IPA has three main key philosophical

underpinnings: phenomenology, hermeneutics and idiography (Smith et al., 2009). Phenomenology focuses on comprehending a human experience (Miller & Salkind, 2002), whilst the hermeneutic circle is used to understand the narratives from participants taken from textual forms (Willig, 2013). Idiography is defined as “the study of any specific situation or event” (Larkin et al., 2006, p. 103). This philosophical foundation uses an in-depth analysis that follows specific procedures and interprets a phenomenon under a particular context (Smith et al., 2009). Hence, the combination of the three main elements of the philosophical points of view: subjective interpretation (phenomenology), analysing texts (hermeneutics) and in-depth analysis of a specific event (idiography) are the underpinnings of IPA (Larkin et al., 2006; Miller & Salkind, 2002; Smith et al., 2009). Willig (2013) stated that IPA is concerned with interpreting the subjective lived experiences of participants. She also highlighted that IPA has a relativist ontology as it focuses on “how participants experience the situation or event” (p. 97).

The focus of this experiential study is on exploring the meanings that Mexican ICs of PwD form during their experiences using ATs and how this type of technology influences their caregiving role. A phenomenological methodology is suitable for this investigation because the aim of this type of methodology is to understand the lived experiences and sense-making of the participants (Creswell, 2007). Phenomenology allows for the thoughts and feelings caregivers have about ATs to be elicited. Phenomenological research permits and guides researchers to interact with participants in an empathic and ethical way (Moran & Mooney, 2002). This research was of a vulnerable group that described their caregiving experiences through in-depth interviews. Such experiences can be overwhelming or difficult to relive. The possibility of emotional distress emphasises the importance of an approach that will allow participants to be interviewed once in an unstructured way with the focus on the depth of their interviews. Finally, the researcher’s philosophical and theoretical views are compatible with the underpinnings of the chosen variation of hermeneutic phenomenological research, interpretative phenomenological analysis (IPA).

IPA was chosen for this research for various reasons. Firstly, there are few known studies which have adopted IPA for the exploration of experiences between humans and technology (Linder & Arvola, 2017; Murray, 2004). Hence, analysing the embodied (Merleau-Ponty’s view as described in section 2.5.1) human-technology relationships with an alternative perspective and method was a way to respond to the Information Systems (IS) research agenda for experiential computing and to expand the methodological options for lived experiences with technology (Bødker, 2017; Yoo, 2010). IPA provides first-person accounts that focus on what is of interest to the participants rather than to the researcher and “opens up the possibility for a critical, decentered examination of the nature and significance of material artefacts in human experiences, thought and action” (Schraube, 2013, p. 14). This means that the participant’s individual accounts will help unravel the embodied interactions (i.e.,

“the interactions with computer systems that occupy our world, a world of physical and social reality, and that exploit this fact in how they interact with us” [Dourish, 2004, p.3]) between ATs and ICs that will provide essential insights about a particular cultural context. Secondly, IPA is a methodology that allows researchers to first analyse their participants using an idiographic focus (providing a focus on their individual experience) and then comparing across to establish the convergences and divergences among them (Larkin et al., 2019). IPA also has a bottom up approach that centralises the research around the participant lived experiences. Finally, IPA is a morally-oriented methodology with empirical sensitivity (Smith et al., 2009) that will provide the researcher with the guidelines and flexibility to adjust the theoretical lens (Ihde, 1990) needed for the analysis of a mediated experience. The following section will describe the research strategy.

3.4 Research Design

Having described the research strategy in section 3.3, this section will detail the way this research was undertaken by following the step-by-step guidelines of IPA (Smith et al., 2009). Section 3.4.1 contains a description of how IPA was conducted for this study. In section 3.4.2, there is a discussion of the limitations of IPA and section 3.4.3 has an outline of the measures taken to maintain validity and credibility in this research.

3.4.1 Conducting IPA

This subsection contains an introduction of the four suggested steps formulated by Smith (1996) and the manner in which they were conducted for this study. Table 3.4.1 below contains a summary of the steps of planning, collecting data, analysis and writing.

How to conduct an IPA study	What to do?
Step 1: Planning	Select sample size, manage your time and consider ethical practices.
Step 2: Data Collection	Select either a semi-structured or in-depth interview and conduct it. You can also use diaries, surveys and documents as data-collecting methods.
Step 3: Data Analysis	Read and re-read interview transcripts, write notes and comments on the data, develop emergent themes and search for connections across emergent themes; repeat these steps for the next transcript and finally look for patterns across all cases.
Step 4: Writing up	Make sure your writing contains an illustrated representation of the clusters and themes, transcript extracts and a narrative account of each participant.

Table 3.4.1. Steps to conduct an IPA study (Smith et al., 2009).

3.4.1.1 Planning

The two main components for planning are: selecting a *sample size* and *time management* (Smith & Osborn, 2008).

It is encouraged in IPA to use a purposive homogeneous *sample* of approximately three to six participants. This is because the complexity of human experiences can turn data analysis into an overwhelming task (Smith et al., 2009). There are many factors that could affect the process of selecting a sample size. Smith et al. (2009) suggested that there are usually three main factors that determine the size of a sample in IPA research: "the degree of commitment to the case study level of analysis and reporting; the richness of the individual cases; and the organisational constraints one is operating under" (p.51). These factors can vary from case to case. Depending on the specifics of the study, these factors will guide the researcher to select a sample size (Smith & Osborn, 2008). Given that the researcher is interested in acquiring a detailed account of a person's experience, quality is a priority over quantity (Smith et al., 2009). In other words, it is

better to have a small sample with good narratives than a large sample that is difficult to comprehend. Thus, it is recommended that although each study's aim is different, a small sample of approximately three to six participants should be used. Although IPA has iterative processes that can continue, in theory, as long as the researcher wants, it is important to stop when meaning saturation has been reached with the sample. Hennink et al. (2017) defined meaning saturation as "the point when we fully understand issues, and when no further dimensions, nuances, or insights of issues can be found" (p.594). Therefore, when the emerging themes were able to answer the research questions and the researcher identified a pattern in participants' responses that was the moment when meaning saturation was reached providing an understanding of how participants engage with the world (Willig, 2013).

The second point for planning is *time management*. Flick (2015) suggested that a Gantt chart should be created for effective date organisation, and setting tasks and milestones clearly and explicitly. Generated in consultation with the researcher's supervisors, multiple versions of Gantt charts were used to guide the study. Smith et al. (2009) suggested the following times as a guideline for novice IPA researchers:

- For every recorded hour of interview, allow seven hours for transcription.
 - The analysis is long and it normally takes several weeks (namely: analysing three cases on a full-time basis may take up to two months).
 - The comparison across the different transcripts takes approximately one week.
- The first draft of the analysis may take up to two weeks.

3.4.1.2 Data Collection

The second step in IPA concerns the data collection methods (Smith, 1996). In qualitative research, the most frequently used data collection methods are interviews, surveys, observation, diaries, and documents (Saunders et al., 2011). Bryman (2012) suggested that when selecting a method for gathering data, the researcher needs to use one that will produce quality data. He explained that quality is achieved by having controlled measurements, for example, making sure the technology used for recording and transcribing is appropriate, creating protocols for interviews or observations, and other measurements.

The following subsections will be a description of the recruitment process and a discussion of the recommended data collection methods for IPA in this section. Smith et al. (2009) suggested that the best methods for IPA data collection are the "ones which will invite participants to offer a rich, detailed, first-person account of the experiences" (p.56). In-depth and semi-structured interviews

are good examples of methods that can capture a person's thoughts and feelings about the phenomenon (Smith et al., 2009; Willig, 2013). In addition to interviews, there are other methods that can also be used in IPA studies, such as diaries, observation and questionnaires (Flowers et al., 2001; Larkin & Griffiths, 2002).

Recruitment of participants

Participants were recruited through the “Federación Mexicana de Alzheimer” (FEDEMA), or the Mexican Federation of Alzheimer in English. FEDEMA was founded in 2002 in Mexico City and it is a non-profit society formed of different support groups, including 18 Alzheimer associations around Mexico (FEDEMA, 2016). The association collaborated with the researcher on the project and from their databases, provided the contacts of informal caregivers from one association. The name and location of the association will not be disclosed to maintain the anonymity of the participants since they all attended support groups in the same location that could identify them easily. No financial incentive was offered to the participants because FEDEMA explained that people under these particular circumstances want to be heard and to participate freely. They explained this is a normal procedure and that the people are used to researchers' interviews.

FEDEMA allowed the researcher to recruit participants by email. Invitations were sent by the allocated association on behalf of the researcher with details of the research and researcher. As few email responses were received, the association permitted the researcher to recruit participants at their support groups in person. The researcher's second approach was through snowball sampling. According to Gray (2013), snowballing is when “the researcher identifies a small number of subjects, who, in turn, identify others in the population” (p.88). To effectuate this approach, the researcher gave a brief announcement at the beginning of the support group meeting. In her speech, she invited any potential candidates to participate and to invite others who could potentially participate. The researcher recruited a homogeneous sample of 21 Mexican informal caregivers from an Alzheimer's Association in Mexico (see section 3.4.1.3 for a detailed explanation of the sample selection and recruitment). Individual appointments were scheduled for all the selected participants at a time of their convenience. All participants were given an information sheet in advance which contained the details of the investigation and an oral explanation of the research (see Appendix 1 for a copy of this).

Inclusion and Exclusion Criteria

Participants were selected who met the following inclusion criteria:

- People who were, or had been, informal caregivers of people in the middle and advanced stages of dementia. For the study, people who had been ICs were recruited since it was advised by the allocated Alzheimer's Society that people going through the experience find it very difficult to manage their time and therefore it would be challenging to find time for an interview. In this study, the characteristics of the middle stage were based on information taken from the Alzheimer's Society website. The middle stage is when a patient starts needing support for basic day-to-day activities, for example, eating, showering, using the toilet, and dressing (Alzheimer's Society, 2017). They can be irascible and become increasingly forgetful. In addition, they can also start showing aggression towards people who are trying to help them. People in the early stages of Alzheimer's disease are not suitable as it is difficult to diagnose dementia in such early stages, and acknowledgement of the condition does not usually occur until it reaches a medium stage. People with advanced dementia may have lost their full mobility and be bound to their beds.
- The participants needed to have used an assistive technology, for example, monitoring cameras, for in-home care as part of their caregiving experience. There was no minimum experience that the caregiver had to have had with the technology before the interview. This decision was made because the aim of this investigation was to capture positive and negative experiences with the technology.
- Informal caregivers had to be of Mexican nationality acquired through birth, not naturalisation. It was important that the participant had lived only in Mexico their whole life. This requirement ensured the participant knew the cultural mannerisms and traditions of the country. By interviewing native Mexicans, an accurate representation of their collective beliefs and values as a society could be collected.

Choosing an interview style

In social science, there are different styles of interviews used for research. The main reason for a researcher choosing this data collection method is that it allows them to explore the participant's knowledge, feelings, attitudes, and values (Cohen et al., 2013). Furthermore, the aims and objectives of the research inform the style of interview (Gray, 2013). Bryman (2012) suggested that the aim of an interview "is for the interviewer to elicit from the interviewee or respondent, all manner of information: interviewees' own behaviour or that of others; attitudes; norms; beliefs; and values" (p.209). This means that, for research purposes, an interview is a data collection

method in which the interviewee provides information to the researcher including insights from their personal perspective (Gray, 2013). There are twelve types of interview approaches that are generally used in social science: structured, semi-structured, unstructured, standardised, intensive, qualitative, in-depth, focused, focus group, oral history, group and life history interviews (Bryman, 2012). Each research strategy normally has its own recommended set of data collection methods, and IPA is no exception (Smith et al., 2009). As mentioned in section 3.3.2, for IPA, the two most frequently used styles are in-depth and semi-structured interviews, as they focus on a person's experience in depth (Smith & Osborn, 2008). In the following subsections, there will be an exploration of these two styles, with a specification as to which one will be used for the research.

In-depth interviews. Saunders et al. (2011) described in-depth interviews as a way to converse in an informal, unstructured manner about a participant's experiences. Legard et al. (2003) suggested that, even though a good in-depth interview appears to be a natural conversation, it has to contain an implicit structure that can be flexible but must be followed by the interviewer. In other words, it is highly recommended to make an interview schedule that contains the set of open-ended questions that the researcher wishes to ask in accordance with their aims, and a plan for any possible difficulties that can emerge in the interview (Smith et al., 2009). Furthermore, in this style, the interviewee's story is interpreted by the interviewer to provide new insights into the studied phenomenon (Legard et al., 2003). This interpretation should contain a reflection of the values, beliefs, feelings, and behaviours of the interviewees (Saunders et al., 2011). In theory, a typical in-depth interview takes approximately one hour or more to be completed (Smith & Osborn, 2008).

Legard et al. (2003) suggested that there are four main characteristics of this style. Firstly, it is both structured and flexible. It is structured in that the researcher needs to know what questions he/she wants to ask, and it is flexible because the interviewee will shape the course of the interview as it progresses. Secondly, the interactive nature of this approach is important, as the participation of both parties is required to generate the information that is needed. Thirdly, different techniques, such as follow-up questions, are used to achieve in-depth answers from the interviewee. Fourthly, the researcher, in acquiring knowledge during their research, will develop a new worldview, particularly of the phenomenon, and the various perspectives surrounding it.

Finally, this approach requires a face-to-face interview, since it is part of the analysis to acknowledge any relevant facial expressions and hand gestures that could say something more about the participant (for example, implicit information) (Smith et al., 2009). The aim of this study was to understand the lived experiences of ICs using ATs for their caring role. Therefore, given

that an insight into the phenomenon under investigation is expected, this type of interview was deemed to be suitable for the research. This is because it would deliver a great understanding of their lived experiences and “facilitates an appreciation of the participants’ priorities and a sense of the relative importance of what the participants talk about and bring to the focus of the interview” (Smith et al., 2009, p. 70). Thus, there are higher probabilities of richer data output for the research with this style.

Semi-structured interviews. Similar to in-depth interviews, semi-structured interviews are those with a defined agenda or schedule that contains the questions that will help the interviewer to remember topics and focus during the interview (Gray, 2013). This approach is also flexible, since the researcher can freely change the direction of the interview to get the answers for their research questions (Willig, 2013). Alternatively, the researcher can create a new question in the moment if this change can lead to a possible new discovery that may be beneficial for the research (Bryman, 2012). Semi-structured interviews are an iterative process as a researcher may start with some questions and realise by the end of the first interview that he/she needs to make changes to the questions, without discarding the data from the first interview (Smith et al., 2009). The questions in this type of interview should provoke the sharing of personal stories (Willig, 2013). Smith et al. (2009) suggested that this type of interview should contain six to ten open-ended questions, along with a couple of closed-ended and rescue questions, in case the topic deviates. They explained that a semi-structured interview lasts between 45 to 90 minutes. Furthermore, various authors agree that the rapport created between the interviewer and interviewee is a crucial factor for the success of this type of interview (Bryman, 2012; Flick, 2015; Whiting, 2008; Willig, 2013). Thus, the interviewer should make the interviewee feel safe, comfortable, and encouraged throughout the process so that talk can be open and free (Smith et al., 2009).

This style is compatible with IPA’s data analysis style, as it allows one to probe meaning from those shared experiences (Willig, 2013). However, Smith et al. (2009) stated that a semi-structured interview limits the researcher’s analysis and the opportunity for a detailed account from the participants, as themes can only be developed from the interview schedule topics. Additionally, they recommended in-depth interviews since IPA’s inductive nature allows exploration from the specific to the general, thus creating richer data. Accordingly, in-depth interviews were the selected method for this research. The following subsection details the way interviews should be conducted, and the approach that was adopted in this study.

Planning the interviews

Before conducting an interview, it is important to inform an interviewee of the approximate length of time of the interview, the main objective of it, and the openness of the researcher to answer any questions they generate while they read the informed consent information (Smith et al., 2009).

Further to that, it is fundamental to set a place for the interview which is safe, quiet, and comfortable to the interviewee (Smith, 1996). These last steps will help to establish rapport with the interviewee, which is essential at the beginning of the interview (Smith & Osborn, 2008). Once the rapport has been achieved, the first question can be asked, with the researcher giving sufficient time for the participant to think and respond freely (Smith et al., 2009). Smith et al. (2009) suggested that “good research interviewing requires us to accept, and indeed relish, the fact that the course and content of an interview cannot be laid down in advance” (p.65). This means that it is likely that the interview schedule will not be followed, completed or phrased as it was written; rather, it will serve as a guide. This should not be a reason to think the interview went wrong (Willig, 2013).

Smith et al. (2009) proposed a key set of questions that can be used in the middle of the interview in order to obtain a richer description of the participant’s experience, namely, “Why? How? Can you tell me more about that? Tell me what you were thinking? How did you feel?” (p.68). These questions can be used particularly if the participant gives generic and impersonal answers (Smith & Osborn, 2008). Once the interview is finished, an important part of the interview procedure is to create a verbatim record of it, describing in detail any non-verbal utterances, for example, laughter, long silences, crying, and so on (Smith et al., 2009).

Conducting the interviews

For this investigation, 21 Mexican ICs of a PwD who used ATs for their caring role were interviewed face to face. Twenty participants decided to have their interview in their homes and one participant at the Alzheimer’s Association office. The day prior to each participant’s interview, the researcher wrote in a personal diary and logged her feelings, thoughts, and anxieties about the participant she was going to interview. These writings were based on the recruitment process interactions, namely, the phone conversations, text messages, email exchanges and face-to-face conversations at their support group. The objective of this exercise was to have a point of reflection and comparison of any pre-conceptions of each participant.

Before the interview started, the participants were asked to read their information sheet, sign their written consent form and answer a demographic questionnaire (a copy of which is in Appendix 1). Their interviews were audio-recorded only and transcribed in Spanish by the researcher. All recordings were stored on the University’s cloud servers and the researcher’s encrypted laptop. A copy of the interview schedule can be found in Appendix 2. The questions during the interviews focused on asking the participant to describe the way they used the technology in their everyday

life, how they felt and thought about it, how their family member with dementia reacted to the technology, their expectations when they first bought the technology and the way this technology was incorporated into their family routine. The aim of these types of questions was to elicit the nature of the usage of ATs during the caregiving experience. Probing questions were used to detail the narrative they shared about their experiences. After each interview, the researcher made a second log on her personal diary about the details, thoughts, feelings, and impressions obtained from the interviewee.

3.4.1.3 Data Analysis

The aim of data analysis within IPA is for the researcher to interpret the underlying meanings and complexities from the phenomena under study (Smith et al., 1997). According to Smith et al. (2009) “analysis is an iterative process of fluid description and engagement with the transcript” (p. 81). Hence, the transcripts from the interviews are the fundamental key for data analysis (Smith, 1996). The six steps are reading and re-reading, initial noting, developing emergent themes, searching for connections across emergent themes, moving to the next case, and looking for patterns across cases. These will be described in the next subsection, along with the rationale for the selection of the final sample and the way participants were analysed using the suggested six steps.

Final sample. As mentioned in section 3.4.1.1, IPA samples are usually small with approximately three to six participants (Smith et al., 2009). Nonetheless, in this study, 21 participants were recruited. This provided the researcher with a data buffer in case some interviews were not adequate for the final sample for this thesis and to purposively select the most informative interviews as discussed below. In addition, the researcher recruited this amount of participants to have enough material for future research and publications related to the topic of IC of PwD. After all the transcriptions were completed, the researcher allocated pseudonyms to the participants. She then created a password-encrypted internal file in Excel to visualise the summary of the participants’ in an orderly fashion. In order to decide which participants to analyse first, the researcher took into consideration the notes kept in her personal diary. Comparing the pre- and post-interview notes from the researcher’s personal diary helped her to identify the quality of the interviews. The richness of the interview was judged according to the extent to which participants were able to express their feelings and explain in detail their everyday experiences. The researcher reviewed her notes under the guidance of her supervisors and selected the five most engaging and complex stories.

These five participants were analysed following the six steps for IPA analysis, which are explained in detail in the next subsection. As a result of the preliminary results of the first five participants,

the researcher decided to assess the feasibility of including participants who had contrasting views to the ones who had already been analysed. For example, if one of the participants from the first group had a supportive family, then from the remaining sample of 18, the researcher looked for cases with a participant that had a poor relationship with their family. This process was made to provide the following contrasting views: hiring a nurse versus caring without extra support; having more than one sibling versus only one sibling; working full time while being a carer versus being unemployed; and caring for the PwD at the time of the interview versus having been a carer in the past. Therefore, the second filter applied to the remaining sample of 18 was their viability for a contrasting view that would illustrate different circumstances under the same phenomena. The number of participants that were selected after the second filter were four, making the final sample to analyse for this thesis, nine. The remaining twelve participants will be divided into two samples of six that are planned for future publications independent from this thesis.

Step 1: Reading and re-reading. The first step for data analysis is reading the transcript of an interview several times to completely understand the data (Larkin et al., 2006). It is recommended that researchers listen to the original recording of the interview several times to detect any emotions in the voice of the interviewee (Smith, 1996). It is done in this way so that the focus of the analysis is the interviewee because, in other methods, the researcher focuses only on the words of the transcripts and not the emotions or reactions from the participants during the interview (Smith, 2004). Any reflections, personal observations or new ideas emerging from the recordings should be written down for theme generation (Smith et al., 2009). The researcher followed this approach and listened to each recording as Smith et al. (2009) suggested. All the emerging notes were written down in the researcher's personal diary.

Step 2: Initial noting. The second step of data analysis is the thorough exploration of the language and semantic content within the transcript (Smith et al., 1997). It is very time-consuming, as it requires line-by-line coding of the transcript, but it allows the researcher to become familiar with it and the encrypted meanings inside of it (Smith, 1996). The aim of this step is to "produce a comprehensive and detailed set of notes and comments on the data" (Smith et al., 2009, p. 83). The main difference between the last step and this one is that the notes from the previous step were made only from listening to the recording, whilst in this step, they also emerged from reading the transcript (Smith, 2004). With the initial noting, the researcher identifies the descriptive, linguistic, and conceptual comments made by the interviewee and with this, realises what matters to them and the real meaning of their worldview (Larkin et al., 2006).

Step 3: Developing emerging themes. In this third step, the researcher should have sufficient

notes and familiarisation with the interviews that will allow for the development of emerging themes (Smith, 2004). The aim of this step is “to reduce the volume of detail (the transcript and the initial notes) whilst maintaining complexity, in terms of mapping the interrelationships, connections and patterns between exploratory notes” (Smith et al., 2009, p. 91). In other words, this is the time to condense data and analyse the notes from previous steps.

Smith & Osborn (2008) suggested that, during this step, the researcher will start to slowly discover emerging patterns that will allow theoretical connection to other transcripts but that are still unique to the analysis. However, Smith et al. (1997) explained that, in order to create themes, the researcher will need to break up narrative flows so that meanings can start to arise. They elaborated that this is part of the hermeneutic circle, as described in section 3.2.4. After the initial noting analysis, the researcher needs to produce themes that will demonstrate a concise statement to describe a category that is a reflection of the researcher’s interpretation of the text (Willig, 2013). In other words, it should capture something that will demonstrate a meaning or reference to the text (Smith, 1996).

Step four: Searching for connections across emergent themes. Step four works with the emergent themes from the transcript, in chronological order, from the previous step (Smith & Osborn, 2008). These themes need to be placed into a functional structure that will allow the researcher to compare all the clusters of related themes, through the use of charts, maps or small pieces of paper (Willig, 2013). This comparative analysis gives the researcher the opportunity to see whether the themes fit into the frame of the research questions and are a true representation of the participant’s account (Smith et al., 2009). Willig (2013) suggested that some of the formed clusters will naturally represent meanings and others will be hierarchical relationships amongst each other. She further explained that, at this point, the researcher should create labels that could be descriptive, a brief quotation or in vivo terms (a direct quote from the transcript) for the clusters that can capture their essence. Once the researcher feels comfortable with the final set of themes, it is important that he/she logs in a diary how the comparative analysis was carried out so that this can be considered while writing the analysis (Larkin et al., 2006). The last step in this search for emergent themes is to create a graphic representation of the clusters through simple tables. These can be made in a Word document (Smith, 2004).

Smith et al. (2009, p.99) recommended that novice researchers should conduct their analysis using paper based (hard copies) for certain steps and could, if preferred, using electronic files to store the final emergent themes. They explain in their specific IPA guidelines that this provides researchers with a better panoramic view of the data collected and it provides faster movement when creating themes. Based on this suggestion, the researcher of this thesis decided to follow this

advice and in Chapter 5 a detailed explanation of the way the analysis was made will be described.

Step five: Moving to the next case. Step five is the analysis of all of the remaining transcripts by repeating all previous steps, until the analysis of the final transcript (Smith & Osborn, 2008). This means that, in theory, each transcript can be considered as an individual case study with particularities that need to be bracketed each time the researcher analyses a new transcript (Smith et al., 2009). The researcher is thus adhering to the idiographic nature of phenomenological research as described in section 3.3.2 (Willig, 2013).

Step six: Looking for patterns across cases. The last step of the cycle deals with the comparison of all the cluster of themes from all individual cases to find patterns among them (Smith et al., 1997). This step requires a great deal of creativity and innovation on behalf of the researcher, as he/she needs to identify hidden meanings, connections or even new interpretations from the final sets of themes (Larkin et al., 2006). A final table is created with the cluster of themes along with subordinate theme labels, quotations that illustrate each theme and a reference to which page or line it belongs (Smith, 2004). In this stage, many themes will be discarded because, after creating the table, they will no longer be meaningful (Smith et al., 2009). It is considered unmeaningful if it does “not fit well with the emerging structure or because they have a weak evidential base” (Pietkiewicz & Smith, 2012, p. 368). The final number of clusters and themes will vary in every case and in the end it should be a meaningful representation of the participant’s account (Smith, 1996).

For this challenging step, all final clusters of themes from all participants were input into an Excel file to visualise commonalities more easily. A detailed description of this step is given in Chapter 5 (section 5.2).

3.4.1.4 Writing up

The final step of the IPA analysis is writing up. The aim of the results section is “to give an account of the data, to communicate a sense of what the data are like, and to offer an interpretation of the data, to make a case for what they all mean” (Smith et al., 2009, p. 109). Some elements that this result section should contain include an illustrated representation of the clusters and themes inside, transcript extracts, and a narrative account of the participant (Larkin et al., 2006). Depending on the project, more elements can appear as this is a creative and innovative stage of the methodology (Smith & Osborn, 2008).

Furthermore, the following sections of the write-up should always be consistent and truthful to the title and main objectives of the project (Smith, 2004). The researcher needs to be coherent with the writing of the report by making sure all of the sections lead to the answering of the research questions. Smith (1996) clarifies that there is not a set of instructions to follow in order to write a

good IPA paper, but it is fundamental to achieve the main objective of the methodology at the end, which is to “represent a dialogue between participant and researcher that is reflected in the interweaving of analytic commentary and raw extracts” (p.110). Hence, this provides a full account of the participant’s experience giving the researcher a better understanding of their worldview.

3.4.2 Limitations of IPA

IPA, like other approaches, has received criticism regarding the suitability of its use (Smith et al., 2009). Willig (2013) highlighted that the three main criticisms found in the literature are: a) the role of language; b) the suitability of accounts; and c) explanation versus description. The following is a brief description of these limitations.

- a) In phenomenological studies, textual forms are the primary source for analysis (Gray, 2013). These can be through the transcript of an interview, personal diary, and field notes (Bloor & Wood, 2006). Willig (2013) suggested that focusing an analysis solely on a text can be a problem because an experience can be perceived and narrated in different ways. Consequently, IPA’s validity and quality come into question. As a response to that critique, Smith & Osborn (2007) explained that “IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people’s talk and their thinking and emotional state” (p. 54). In other words, text in IPA directly represents the participant’s feelings, thoughts and beliefs towards the experienced phenomenon within a particular context, rather than the phenomenon itself.
- b) Tuffour (2017) suggested that one of the main concerns of IPA is the richness of an interview, that is, how likely is it for a participant to express their experiences in a way that is suitable for the researcher’s study. Moreover, Cioffi (2003) argued that not all people are able to communicate their physical or emotional experiences accurately. These two arguments open the debate about the suitability of accounts. It can also be argued that language barriers between the researcher and participant could be problematic as people tend to express emotions through metaphors (Kövecses, 2003). Lastly, for IPA, the question has arisen as to whether vulnerable participants with speech impediments (for example, due to medical reasons) and children, could be suitable candidates for this method as evidently they may not be able to express themselves extensively as the approach requires (Willig, 2013).
- c) Willig (2013) explained that phenomenological research, including IPA, is, to a degree, dependent on the researcher’s intuition and creativity to comprehend the worldview of the participants, given that the analysis is subjective. In short, the belief in this type of approach is that

presuppositions from the researcher may cloud the purity of human experience. Therefore, the focus should be on deciphering the perception of the participants (Smith et al., 2009). This is accomplished through a series of already-established procedures that will help with the analysis of statements extracted from interviews that will later on form themes (Crotty, 1998). The problem with this is that the nature of this approach answers only how questions, rather than the whys. Hence, phenomenology only describes the meanings embedded in the experience, rather than explaining why it happens. This way of thinking has led to questions being raised about the credibility of actually understanding the phenomenon.

3.4.3 Validity and Credibility

There are different opinions among qualitative researchers about the most appropriate considerations to make to ensure the validity and credibility of a study (Angen, 2000; Gray, 2013; Guba & Lincoln, 1994; Willig, 2013). For instance, Gray (2013) and Guba & Lincoln (1994) argued that validity is achieved through the coherence of the theoretical perspectives with the underpinnings of the methods. In the same vein, Angen (2000) suggested an emphasis on ethical procedures and considerations of the study, along with a substantive understanding of one's own biases through self-reflection. Notwithstanding this, for this investigation, the advisory guidelines from Smith et al. (2009), who are the most prominent authors on the subject of IPA, were followed. The two suggested approaches are Yardley's criteria and independent audits. These assessment guidelines will be described below.

3.4.3.1 Yardley's Criteria

This approach was created by psychologist Lucy Yardley and it is composed of four main principles for assessing the validity and credibility of the research (Yardley, 2000). The following descriptions are based on the two main papers in which she addresses these elements (Yardley, 2000; Yardley, 2017). The first essential principle is *sensitivity to context*. Yardley (2000) referred to this as the way a researcher proves the sensitivity of the subject through the presentation of a coherent theoretical and philosophical context. She also specified that when the research is phenomenological, it is advisable to provide a detailed description of the philosophical choices to have a good foundation for the analysis. Smith et al. (2009) also explained that, because the researcher is making sense of the participants' perceptions, this principle is used in IPA when the researcher explains the rationale of the study during data collection by using an empathic approach with participants and when analysing the data. Another example of this principle is the demonstration of the participants' extracts to support the researcher's results (Smith et al., 2009).

The second principle is *commitment and rigour*. This element is explained as the transparency

that the research provides in terms of the data collection, analysis, and results (Yardley, 2017). It is fundamental that a researcher is capable of showing thoroughness and coherence of their work. Yardley (2000, p. 222) suggested that, for a phenomenological study, the “use of prolonged contemplative and empathic exploration of the topic together with sophisticated theorising” are good practices. For the specific case of IPA, rigorous commitment can be shown through the interviews, because a rich interview is a reflection of the personal investment a researcher has made in creating rapport with the participant (Smith et al., 2009). Finally, rigour can also be emphasised by the appropriateness of the sample, the depth of the interpretations, and the idiographic focus.

The third quality assessment is *transparency and coherence*. Yardley (2000) described these two as the ability of the researcher to provide clarity of their work. In other words, this is how a researcher presents, in detail, the way the analysis was conducted and how the researcher found the presented results. Smith et al. (2009) suggested that a good approach for complying with this principle is to provide a coherent narrative that is pleasant to read, the provision of tables and photographic evidence of the way the analysis was carried out, and finally, that the research has an evident phenomenological and hermeneutic focal point.

The fourth characteristic is *impact and importance*. This refers to the potential contribution and utility the piece of work might have after completion (Yardley, 2000). In IPA, this impact is tested by selecting a topic that is interesting and relevant to the area of research and that could create awareness of an unheard lived experience (Smith et al., 2009).

3.4.3.2 Independent audits

According to Smith et al. (2009), there are specific elements of the research that can be traced and audited by a person who is not involved in the project, or by the researcher, for credibility. These elements are “initial notes on the research question, the research proposal, an interview schedule, audiotapes, annotated transcripts, tables of themes and other devices, draft reports, and the final report” (p.183). They suggested that auditing is a good practice, because it will provide a step-by-step guide of how the research was conducted. The two most common approaches for auditing are: 1) collecting all of the suggested elements and asking a researcher who has no relation to the project to conduct an audit; and 2) asking the researcher’s supervisor to check, question, challenge or criticise the recommended elements (Smith et al., 2009). In accordance with the suggested approaches for validity and credibility, the procedures outlined in table 3.4.3 were followed for this research.

User element	Procedure
<i>Sensitivity to context</i>	<ul style="list-style-type: none"> A detailed description of the adopted philosophical perspective was provided (see Section 3.2). Verbatim extracts of the participants were used to exemplify arguments (see Appendix 3 and 4). The researcher has kept a personal diary used for reflexivity purposes. During the analysis phase, the researcher had to go back to the recordings and personal diary multiple times to really engage with the emotions of the participants.
<i>Commitment and rigour</i>	<ul style="list-style-type: none"> During the recruitment phase, the researcher volunteered at the allocated Alzheimer’s Association, to establish rapport with potential participants and to answer face to face any potential questions they might have of the investigation. Interviews were done at participants’ home for their convenience as they had to care for their family member with dementia.
<i>Transparency and coherence</i>	<ul style="list-style-type: none"> To provide clarity in this study, the researcher provided in the Appendices, photographic evidence of the way the analysis was done, an example of the interview questions and questionnaire and the invitation sent to participants. Throughout this thesis, various tables were used to synthesise elements of this research. The philosophical stance of the researcher is clear and consistent with the theoretical underpinnings of IPA.
<i>Impact and importance</i>	<ul style="list-style-type: none"> The findings of the research contribute to the field of dementia care research.
<i>Independent audit</i>	<ul style="list-style-type: none"> Audits were conducted for every participant’s analysis with the primary supervisor. An independent audit was made by a researcher with no relation to the project.

Table 3.4.3 Validity and credibility procedures followed for this research.

3.5 Ethical considerations

Ethical considerations are imperative in any piece of research since they protect the well-being, privacy and rights of the humans that participate in interviews or experiments (Orb et al., 2001). It is important to monitor ethical practice throughout the collection and analysis phase of research, with constant reflection and inspection into the participant's wellbeing (Gray, 2013). Research with ICs of PwD is considered sensitive and therefore presents multiple ethical challenges (Bolmsjö et al., 2006). The ethical considerations that were followed for this study act in accordance with the University of Sheffield's ethical requirements which subsume the principles of the British Psychological Society (BPS). The four ethical principles stated on the BPS (2018) Ethics Committee's code of ethics and conduct are *respect, competence, responsibility* and *integrity*.

The principle of *respect* refers to the way a researcher protects a participant's dignity, which includes addressing their confidentiality and rights with sensitivity (BPS, 2018). One of the reasons this principle is fundamental in all qualitative research is to avoid harm to participants (Smith et al., 2009). In this particular study, harm could have been done through participants talking about their lived experiences (see table 3.5.3 to learn about the steps put into place to respond to participants who could potentially become distressed). How someone may be affected emotionally or psychologically can be difficult to predict, especially if the experiences they are recalling were traumatic (van der Kolk et al., 1985). Therefore, it is imperative to communicate to participants every aspect of the research including, but not limited to: the aim of the research, the information that will be collected, the name of the researcher, the approximate time a participant will be needed, and how confidentiality and data storage will be managed (Gray, 2013). It is very important to emphasise that participants should provide their written or verbal consent before the data collection takes place (Willig, 2013). The second principle is *competence*. Competence pertains to the researcher's skills and preparation for the research (BPS, 2018). The principle of *responsibility* concerns the researcher's professional attitude in ensuring that no participant is harmed during or after their interview (BPS, 2018). The last followed principle was *integrity*. BPS (2018) defines it as "being honest, truthful, accurate and consistent in one's actions, words, decisions, methods and outcomes" (p. 7).

The following subsections will describe how the ethical principles were implemented in the present study. Section 3.5.1 provides the procedures followed to ensure participant's dignity and confidentiality. Section 3.5.2 describes the rationale and details of the conducted pilot study. Section 3.5.3 outlines the procedures followed to ensure the participants and researcher's safety.

3.5.1 Protecting participants' dignity and anonymity

For this study, it was agreed by the researcher and supervisors to avoid disclosing the location of the association to protect the anonymity of the participants. This issue was addressed by clarifying and verbally reassuring each participant, as well as through the consent form, about the potential risks of being identified. This took place before any data were collected. The participants were informed that the researcher's supervisors were also going to have access to their data and that the results of the study could be used for future publications.

This study was compliant with this principle of respect through informed consent. Informed consent refers to the right of every participant to be fully informed about what the study constitutes (Silverman, 2016). All participants were given a paper-based information sheet and consent form on which to provide a written signature on the day of their interview. This form included information about the purpose of the research, the different topics to be discussed during the interview, the possible length of time of the study, their right to withdraw at any point and how the data would be stored and protected. Before signing their consent forms, all participants were given time to think and were also asked the following questions verbally: 1) Do you have any questions or concerns about the research? 2) Do you understand that you can withdraw from the interview at any point without providing reason, or decline to answer any question? 3) Can you confirm that your participation is voluntary? If the participant agreed to these questions, then they were provided a pen for signing the consent form. Copies of the information sheet, an example of the informed consent form and the approved ethics form are provided in Appendix 5.

In accordance with ethical principles, the participants' data were encrypted and stored on the university's cloud servers and on the researcher's encrypted and password-protected laptop for the length of the study. Participants' anonymity was ensured by assigning pseudonyms that were used throughout the analysis. The study received ethics approval in accordance with the University of Sheffield's Research Ethics Policy on the 17th of October 2017 (the letter of approval is provided in Appendix 5).

3.5.2 Pilot Study

In compliance with the principle of competence, and to prepare for this research, the researcher conducted a pilot study with the aim of strengthening her interviewing skills. The objectives were to improve the researcher's interviewing skills and to evaluate the appropriateness of the interview schedule. The ethical application for this pilot study was approved on the 15th of August 2017 by the University of Sheffield's ethics reviewers. A copy of this document can be found in Appendix 5.

For the pilot, data were collected from in-depth interviews. Five research students were recruited from the University of Sheffield's Information School. The participants were chosen due to their accessibility and proximity to the researcher so that the researcher could test the interview guide and data collection tools in a convenient manner. Each participant was interviewed individually once for approximately 90 minutes. The process took place in the Information School's iSpace meeting rooms, where the participants' interviews were audio-recorded with the consent of the participants. The obtained data were stored on the University's cloud servers and the researcher's encrypted laptop, in accordance with the University's requirements. A week prior to their scheduled interview, the participants were emailed and asked to create a fictional story (the guideline of the scenario was provided by the researcher) where they were the primary caregivers of a family member with dementia and they were actively using ATs in their caring role. In addition, the email stated that at any point during the interview, the participant was free to improvise their story. The questions were focused on asking the participant to describe the way they used the technology and how they made sense of it. The results of this pilot study were not used with the rest of the data from this research but they helped to develop the researcher's interview technique.

3.5.3 Protection and well-being of participants

As mentioned before, this research involved vulnerable participants (ICs) and a sensitive topic (lived experiences as caregivers). The researcher acknowledged that during the interview, caregivers could experience some feelings of distress as they were to share personal stories of their life that could be difficult for them. As a consequence, two strategies were established to manage and ensure the protection and well-being of participants. The first strategy was to reassure the participant that the interview could be stopped at any time if they wished. At this point, the researcher could offer some time for the participant to take a break, and to have the water and tissues that she had prepared. The second strategy was that, with the agreement of the allocated Alzheimer's Association, free individual counselling could be offered, at no cost, to any participant that experienced distress after their interview.

All interviews were undertaken in Mexico and participants were able to choose the location for the interview. The researcher is of Mexican nationality and resided in the country for 28 years, meaning that Spanish is her native language and she knows the culture intimately. It is important to note that all participants were registered in the official databases of the Mexican Federation of Alzheimer's as clients who received counselling and support through specialised groups. This means that social workers from the association had their contact details and knew the potential participants personally. In order to keep the researcher safe, there was a special system in place, made between the researcher and supervisors, in case of an emergency or unforeseen circumstance. The table below, Table 3.5.3, details the way the system in place for three specific scenarios: 1) interviewing

a participant at a public place or their home, 2) what to do in case of a medical emergency and 3) how to act upon a violent, abusive or uncontrollable situation during the interview. All elements described in Table 3.5.3 are in line with the University of Sheffield policy for field work.

Potential scenario	Steps to follow
Interviewing a participant at a public place or their home	<p>1) Inform a close relative or friend, through text message, about her location upon arrival to the agreed place. The location she will provide will be just the street name and not the house number to ensure the participant's anonymity. Due to the time zone differences, it will not be practical to notify her supervisors. If the researcher does not inform about her location in the first 15 minutes since she left the vehicle, the friend or relative should call her. If there is no response after 3 consecutive attempts, the friend or family member should report this situation to the police.</p> <p>2) Upon completion, the researcher will text once more her relatives or friend that she is leaving the place safely. If the researcher's friend or relative does not hear from her after two hours since the initial time of the agreed appointment, the relative or friend should phone her... If there is no response after 3 consecutive attempts, the friend or family member should report this situation to the police.</p>
A medical emergency	<p>1) The researcher will ring the emergency services that she will have saved previously on speed dial.</p> <p>2) The researcher will proceed with what authorities or emergency services recommend and then notify relatives or friend from Mexico about her whereabouts.</p> <p>3) Notify supervisors about the incident.</p>
A violent, abusive or uncontrollable situation during the interview.	<p>1) The researcher will stop the interview and get out of the place as fast as possible.</p> <p>2) Once she has reached a safe place, she will notify the family member or friend who brought her to the interview.</p> <p>3) Ask for a taxi/uber from her mobile phone.</p> <p>4) Notify supervisors about the incident.</p>

Table 3.5.3 Protection and well-being of participants

The next section, Reflexivity, will describe the purpose of exercising reflexivity and the way it was conducted in this study.

3.6 Reflexivity

Willig (2013) suggested that IPA requires reflexivity which means “an awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining ‘outside of’ one’s subject matter while conducting research” (p.10). In other words, reflexivity in this instance acknowledges the dependency on the researcher’s perspective and prevents their own assumptions or opinions from tainting the results (Charmaz, 2006). Nonetheless, this does not mean that the researcher’s worldview is incorporated into the final writing, but that the researcher uses their knowledge in the subject to interpret the participants’ comments (Smith, 2007). Reflexivity was exercised following three main procedures during the phases of data collection, analysis, and results for this study. Section 3.6.1 explains the rationale behind writing in a reflexivity diary before each interview. Section 3.6.2 describes the procedures that were implemented after each interview. Section 3.6.3 described the way reflexivity was implemented during the analysis phase. Finally, section 3.6.4 presents a first-person reflexivity statement made by the researcher of this investigation to provide transparency of what her preconceptions were during the methodology stage.

3.6.1 Writing in the reflexivity diary before each interview.

Before each interview, the researcher decided to write down in a personal diary all her assumptions and preconceptions of each recruited participant. With a total of 21 individual entries, the researcher wrote her first impressions, personal opinions, expectations and feelings towards each participant. This exercise was very valuable as it allowed the researcher to bracket (see Section 2.2) the pre judgements made during the recruitment process based on the participants’ personalities, expressions, moods, stories, or even their voice. Each entry also reflected the researcher’s fears and anxieties around the project.

3.6.2 Notes after each interview

After each interview, a set of procedures was implemented as part of the reflexivity for this research. These included the storage of the interview recording and paperwork following the ethical measures stated in section 3.5 and the written reflection of the researcher post-interview. These reflections were logged as individual entries in the researcher’s personal diary. The main thoughts included concerns, ideas, initial interpretations, unexpected reactions, and opinions formed of the interviewed participant. These involved the researcher’s self-awareness of mistakes made during the interview and any issues around the procedures that needed to be followed post-interviewing (namely, uploading the interview recording and encrypting files).

3.6.3 Reflexivity during the analysis

As a continuation of the previous two steps, the researcher reflected upon the results that emerged during the analysis. During the reading of the transcript in progress, the researcher wrote, without restrictions, any instinctual first thoughts about the interview. These notes were then re-read, processed, and compared with the diary entry of the participant in progress. This procedure prevented the researcher's formed opinions from corrupting the emerging results. In the following chapter, reflexive boxes will be used after each participant's account and the group analysis results to reveal how the researcher's positionality and pre-judgments influenced the interpretations. Finally, during independent audits, all findings were questioned and adjusted in line with the feedback received from the auditor.

3.6.4 Reflexivity statement

I have been interested in both technology and medicine since I was a child. I come from a family of medical doctors on both my mother's and father's sides. The earliest memories of my life were centred on hospitals. Although I have never intended to study medicine, I consider myself a person with an above-average understanding of how the human body works or how it can be fixed. During family gatherings, I learnt how to cure fevers, what to do if I ever had a broken bone, and the early signs of a stroke. As a result of my unconventional upbringing, I developed a huge respect for medical doctors, nurses, and trained carers. My innate curiosity and respect for the field made me stand side by side with my uncles and aunts who cared for my late grandmother during her difficult last years. My grandmother was a tremendous influence in my life. I spent many hours under her care every time my parents had to go to work. My grandmother had a series of health complications that included vascular dementia as a result of a stroke. This event occurred during my undergraduate degree, where my passion for technology grew. I watched her and my entire family suffer from this disease. My grandmother was no longer the same person in the last years of her life. I remember I was angry and stopped visiting her because I felt hurt and confused by her behaviours toward me. After her passing, my family was drowned in debt and divided as guilt and resentment grew over the years. This disease broke my family and left me wondering if I could do something. I am passionate about technology and fascinated about the ways it is immersed in our lives. For my PhD, I wanted to study something related to technology and dementia. Therefore, following my instincts and inspired by the hard work of informal caregivers, I decided to undertake this research. I, the researcher of this study, acknowledge that my background in information systems and my country of origin might be seen as possible elements that could bias the interpretations resulting from this investigation. I was born and raised in Mexico and understand the idioms, sayings, political discourses, cultural values, and traditions of this region. Having all these elements to my advantage helped me have a clear understanding and space to interpret the

participants' views more thoroughly. I understand that this situation might seem convenient for some, as a person who does not understand this country might feel I am being biased. As a preventive measure regarding this possibility, I state that I have no relation whatsoever with anyone who participated in this research. The allocation of the Alzheimer's Association and recruitment process was made through the people from FEDEMA, based on the number of potential people I could interview. With this in mind, the first contact was made through the people from the Alzheimer's Association, who kindly sent an email to participants on my behalf. I also clarify that my views for the interview and analysis process are inspired by ethnocentrism and cultural relativism. This means that I aimed to see the world from the Mexican perspective (namely, understanding the politics, sayings, and so forth) and also I believe that this particular sample can be understood properly by taking their cultural context into consideration. However, I fully disclose that this was not the adopted approach for the discussion and literature review, in which my views remained bracketed. Specifically, for the findings section, a double hermeneutic (see Section 4.2.3) was employed. Exercising this allowed me to interpret my participants recursively since the approach acts as a second layer of interpretation. In other words, once I finished the analyses and had all my final categorised themes, I was able to step back from the results, reflect, and critically analyse the results against identified elements within their context. I am also fully aware that, at the time of the recruitment and interviewing process, people might have seen me as a technology consultant or an expert that could advise them of products that could help them during their lived experience. In order to avoid this situation, I clarified my intentions and credentials before the scheduled interview to participants. As I have no previous training or experience in research, I decided to leave an evident auditable trail to ensure that my work remained as transparent and as clear as possible.

3.7 Conclusion

This chapter has contained an in-depth description of the methodology followed for this research. In section 3.2 Research Philosophy, the qualitative nature of the study and the researcher's philosophical stance were revealed. The views from the constructivist paradigm were adopted to accommodate the interpretative epistemological views of the analysis. The relativist ontology permitted the inductive exploration of the subjective experiences that helped in the creation of the participants' accounts. Section 3.3 described the selected phenomenological research strategy called IPA in detail and discussed other considered approaches. In section 3.4, Research Design, the step-by-step recommended guidelines by Smith et al. (2009) were described and followed. This section included the fundamental phases of data collection and data analysis. The limitations of IPA and validity concerns were also briefly discussed. Section 3.5 detailed all the ethical considerations and safety measurements taken for this study. To conclude the chapter, in section 3.6, the researcher acknowledged and declared her pre judgements and opinions about the phenomenon under investigation. Reflexivity was exercised to avoid any biases or favouritism that could taint the results. In the following chapter, there will be a presentation of the results from the idiographic analysis.

Chapter 4: Results

4.1. Introduction

In Chapter 3, a comprehensive description of the research philosophy, strategy and design were presented. These components formed the pillars of this investigation. Together, they reflect the way this research was rationalised and completed. Chapter 4 introduces the results from the phenomena under investigation of this research. The following Section 4.2 describes the way the data from this research was analysed and interpreted. Section 4.3 introduces the results from the idiographic analysis of all nine participants. Finally, Section 4.4 concludes the chapter. This chapter, paves the way for the next stage of the analysis, Chapter 5, in which the results of the group analysis are presented.

4.2 Analysing the participants

Prior to the detailed description of the findings from this research, it is important to provide contextual information to unravel the worldviews of the participants. In this study, worldview is defined as the “set of mental categories arising from deeply lived experience which essentially determine how a person understands, feels and responds in action to what he or she perceives of the surrounding world and the riddles it presents” (Sire, 2015, p. 43). This definition is Sire's (2015) interpretation of the teachings from the hermeneutic philosopher, Wilhelm Dilthey, whose contributions are known for his focus on human experiences (Makkreel, 2016). This view emphasises the uniqueness and complexity of human experiences. For instance, it attempts to explain that, through interactions and relationships with objects, culture and language, people create a personal understanding of the world, that together with their lived experiences form their worldview (Smith et al., 2009). In line with the phenomenological tradition, this study considered the participants' physical bodies as sensory instruments that informed the biological, psychological and sociological components of the world around them (Takacs, 2003; Merleau-Ponty, 1962). This assumption was made to explain how present and past experiences shaped the informal caregivers (ICs) perspective of the world (Takacs, 2003). All the data were collected in the Spanish language, therefore, prior to conducting the analysis, all transcripts and relevant diary entries were translated to English by the researcher. All recordings were stored on the University's cloud servers and the researcher's encrypted laptop. The length of each interview varied between each participant. The shortest lasting 26 minutes and the longest 1 hour and 35 minutes. In line with the idiographic commitment of Interpretative Phenomenological Analysis (IPA) to the particular, each participant in this study was analysed and evaluated as an individual case study. Once all the participants were interpreted, the individual accounts were subjected to an across-case analysis. Therefore, the participants' worldviews were revealed after

completing all the steps from the IPA analysis. The following subsections will describe the steps taken for the idiographic analysis and the elements that supported the interpretations of this study.

4.2.1 Description of the sample

The following are the demographic details of the final sample that complement the understanding behind their lived experiences. All the participants were born and raised in Mexico (n=9). At the time of their interview, the sample had a mean age of 56.78 years (range: 49 to 64 years). From the sample, one participant was in the late 40s, six in their 50s and two in their 60s. The predominant gender was female (n=8, 89%) with all of them reporting being mothers at the time of their caring role. In terms of their caring role, they all identified themselves as the primary caregivers (n=9) of a parent affected with a type of dementia. Two (22%) participants were working full-time, three (33%) part-time, three (33%) were unemployed and one (11%) identified as retired. The average time spent caring per day was 15 hours (n=9). Married (n=5, 56%) was the most common relationship status reported among participants, followed by widowed (n=2, 22%), divorced (n=1, 11%) and single (n=1, 11%). All participants' reported their assistive technology purchase was for home safety reasons(n=9).

Other quantifiable observations among the participants were extracted from the individual interviews and the overall analysis. For instance, at the time of the interviews three (33%) participants were currently living the experience of being a carer, whilst the six (67%) remaining participants narrated their past experiences as caregivers. The assistive technologies acquired by these caregivers were surveillance cameras (33%), emergency buttons (22%) and the combination of a surveillance camera with either a baby monitor (22%) or a voice recorder (22%). Three (33%) participants reported hiring nurses to help them with their caring responsibilities and the remaining six (67%) acted as the only caregiver. Table 4.2.1 presents a summary of some of the demographic characteristics from the final sample. Within the table, the first column presents the participants with their allocated pseudonym, followed by their gender, employment status, the assistive technology (AT) used during their experiences and the status of their person with dementia (PwD).

Participant	Gender	Employment Status	AT used	PWD Status
Sofia	Female	Full-time	Surveillance camera and baby monitor	Alive
Claudia	Female	Part-time	Surveillance camera and voice recorder	Deceased
Valentina	Female	Part-time	Surveillance camera and baby monitor	Deceased
Camila	Female	Unemployed	Surveillance camera	Alive
Maria	Female	Unemployed	Surveillance camera and voice recorder	Deceased
Frida	Female	Unemployed	Surveillance camera	Alive
Pablo	Male	Full-time	Surveillance camera	Alive
Margarita	Female	Part-time	Emergency button	Deceased
Gloria	Female	Retired	Emergency button	Deceased

Table 4.2.1 Demographic characteristics from final sample.

4.2.2 The idiographic analysis

This section presents the procedure followed for the idiographic analysis from this research. In Chapter 3, idiography was described as the study of particular occurrences with people, events or historical moments in a detailed and systematic manner (Larkin et al., 2006). In this research, the researcher was trying to understand how the ICs perceived and understood their experiences with ATs. To achieve this, their personal experiences were explored to identify potential patterns that can complement existing theories or concepts. The aim of this analysis was to give a ‘voice’ to the IC’s experiences, reflections, sense-making process and concerns about their use of ATs during their caring activities. This ‘voice’ emerged from their narrative and was then interpreted to understand the meanings they placed on their interactions with ATs. These interpretations aim to provide a comprehensive report of the IC experiences to inform policymakers, design and developers about practice. All interpretations from the idiographic accounts followed the hermeneutic-phenomenological approach. IPA’s phenomenology is interpretative, meaning that in this study, the focus was to understand the perspectives of the ICs on ATs and the contextual factors of the experiences that influenced the sense-making of the ICs (Lopez & Willis, 2004).

4.2.3 The different lenses used for the interpretations

As mentioned in Chapter 3, the first step of the IPA analytic process is reading and re-reading individually and line by line each participant’s interview transcript (Smith et al., 2009). During this step, the researcher carefully read the participant’s transcripts and listened to their audio recordings, multiple times, to annotate any comments, concerns, observations and understandings that emerged from the transcripts. These annotations were written on the printed transcript of each participant and any early feelings were recorded in the researcher’s personal diary. Moreover, the researcher continued with steps two, three and four from the IPA analysis (see Appendix 3 for photographic evidence). These steps were executed in the following order: initial noting, developing emerging themes and searching for connections across emergent themes. This was a complex, detailed, creative and time-consuming process that required a systematic approach. The researcher created the following strategy for each participant’s account:

1) The first step was to print the participant's transcript in double space and wide margins. This conventional approach provided the flexibility to work at convenient places (for example, flight commuting) and with visual amplitude. Each participant was analysed as an individual case to respect the idiographic nature of IPA. Three different coloured highlighters were used to represent the descriptive, conceptual and linguistic semantic contents of the interviews, e.g., green was used for conceptual, orange for descriptive and pink for linguistic content.

2) The second step was to establish the semiotic language that was going to be analysed from the transcripts. The researcher adopted Smith et al.'s (2009) suggested categorisation for semiotic content: descriptive, linguistic and conceptual. Descriptive comments were considered those who described something of significance and/or made an experiential claim (e.g., I feel happy). Linguistic comments were considered as the unique language nuances found in the participant's narrative (e.g., the use of metaphors or analogies). Conceptual comments were the ones that provided objects of concern to the participants (e.g., relationships, opinions). Semiotics are important in this research as they "provide formalisms for the description and explanation of individual sense-making" (Rosa, 2008). After this classification, the researcher handwrote exploratory comments on the printed transcripts of the aforementioned semiotic contents (see Appendix 3). All transcripts were in Spanish and the selected quotes were translated to English for the analysis. In some cases, the researcher consulted with an expert on Mexican-Spanish discourse, to understand and translate metaphors and generational Mexican sayings. The final interpretation of these specific commonalities was discussed and approved in a meeting between the expert and the researcher who resides in Mexico.

3) The third step was to create structures in which the exploratory comments from the previous step were organised and recorded. All tables from this research were created using MS Word. The aim of creating the tables was to store electronically the handwritten data from step two. Table 4.2.3a shows the headings that were used in the tables to identify the most relevant data at this point. The column labelled transcript stored the extract that was analysed. The column with initial noting/exploratory notes was used to write the handwritten annotations from steps one and two (namely, from diary and exploratory comments). The semiotic column was used to define whether the content was descriptive, conceptual, or linguistic. The designated column for line was to note the line(s) in which the extract was situated within the transcript. The last column was for noting the emergent themes.

Transcript	Initial Noting/Exploratory notes	Semantic Content	Line	Emergent Themes
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Table 4.2.3a. The headings used for tables in steps two and three.

4) The fourth step was to print all of the emergent themes identified from step three, cut them and place them on a flat surface. This approach provided the researcher with visual amplitude that facilitated the process of pattern recognition of the themes. More photographic evidence of this procedure can be seen in Appendix 3. Once patterns have been established, names were allocated to each cluster of themes. The researcher then compared, contrasted and retreated back and forth to think about all the information until all emergent themes were part of a cluster. Emergent themes that were not compatible or relevant for the study were placed aside at this stage, since they would be used later for the across-case analysis. A relevant name was assigned to each cluster to represent the overall idea or meaning that emerged from that group. The clustered data were then stored in tables. Figure 4.2.3b demonstrates how the populated tables looked. Each table contained the cluster name at the top of the table identifying the group. Under the categorised cluster, the first column displays the emergent themes, followed by the line indicating the location of the emergent theme within the transcript and, lastly, keywords taken from the extract as a reference to the theme.

Cluster 1: Irreconcilable family differences		
Emergent Themes	Line	Keywords
Sued siblings out of fear	258-261	I had to report
Blames her siblings	290-292	They said
Afraid of siblings	160-161	Legal safeguard
Exhausted of family conflicts	261-263	Started legal problems

Cluster 2: Frustration		
Emergent Themes	Line	Keywords
Frustrated that siblings don't support her	255-258	Nobody supported me
Frustrated that siblings oppose her views	296-297	Mess that was made
Frustrated that no one believed her	297, 300	Believe me

Figure 4.2.3b. Example from table used during step four.

5) The last step was to interpret all the data from the analysis (namely, from the tables). The process of interpretation through the lens of IPA is influenced by the views in hermeneutic phenomenology from philosophers Schleiermacher, Heidegger and Gadamer (Smith et al., 2009). The interpretations from this research followed Schleiermacher's focus on the analysis of linguistics and the lay interpretation of the participants' psychology (namely, the meanings behind the participant's emotional state) (Marinā, 2006). This study also acknowledged Heidegger's contribution to hermeneutics regarding pre-understandings/pre-experiences of the researcher about how the phenomenon under investigation influences the interpretation process (Larkin & Thompson, 2012). However, with Gadamer's approach to exercising reflexivity through a double hermeneutic (see section 4.2.4), this research addressed the aforementioned limitation (Smith & Osborn, 2003). This study was also guided by Gadamer's (1976) input on hermeneutics that suggested history, culture, and linguistics as factors that influence people's sense-making processes. Therefore, all the interpretations made during the analysis were guided by the ideas of the preceding philosophers and adhered to the ideology of the hermeneutic circle (see section 4.2.4). This conceptual process will be described in the following subsection.

4.2.4 Using the hermeneutic circle

The hermeneutic circle analysis is carried out by levels and in a non-linear manner; the 'parts' and the 'whole' of a text are analysed against each other, to add new layers of interpretation (Gadamer, 1976). Smith et al. (2009, p. 28) explained that "to understand any given part, you look to the whole; to understand the whole, you look to the parts". In other words, this suggests that the researcher analyses at macro (the 'whole') and micro (its 'parts') levels of the text to create new knowledge and/or reference the meanings that emerge from it. Table 4.2.4a exemplifies this statement.

	<i>The parts (Micro)</i>	<i>The whole (Macro)</i>
Level 1	The single word	The sentence in which the word is embedded
Level 2	The single extract	The complete text
Level 3	The particular text	The complete oeuvre
Level 4	The interview	The research project
Level 5	The single episode	The complete life

Table 4.2.4a. Adapted from Smith et al., 2009; p. 28

The first column from Table 4.2.4a locates all the micro components from the text that are referred to as the ‘parts’. These ‘parts’ can be analysed in relation to the ‘whole’, which in this case are the macro elements situated in the second column. Each ‘part’ analysed against a ‘whole’ has the potential to elicit new meanings. For example:

<i>The parts</i>	<i>The whole</i>
1)“I realised” 2)“Could not stop thinking” 3)“Called my daughter”	Last week I went on a trip. My brother stayed with her [ill mother]. Then I realised that I could not stop thinking about her [ill mother]. So I immediately called my daughter and asked “hey, is your grandma ok?” (Camila, 158-160)
Interpretations (the parts in relation to the whole)	
The parts 1) Camila had an epiphany in the middle of her trip that made her anxious. 2) Camila acknowledges that even when she is apart from her mother, she constantly thinks and cares about her wellbeing. 3) It appears that Camila trusts her daughter enough to share her newfound anxiety.	The whole Camila does not trust in her brother’s caregiving skills and feels anxious that he might neglect their mother. She trusts her own daughter, so she called her to get updates and avoid confronting her brother. Being away from her mother has made her trigger obsessive thoughts about care.

Table 4.2.4b. Example of how the hermeneutic circle was carried out in this research.

As shown in Table 4.2.4b, Camila’s extract was analysed as ‘parts’ in relation to the ‘whole’. In the previous example, the interpretations from the ‘parts’ reflect the different meanings that can emerge from the micro analysis of words. However, when referenced against the ‘whole’, the macro, the cumulative meanings from the ‘parts’ transform, refine the interpretation of the experience. This concept is commonly illustrated as a circle because it represents how the knowledge that surfaces from the text, is metaphorically moving back and forth, refining the meaning of the ‘parts’ and ‘whole’ (Debesay et al., 2008). Figure 4.2.4c. illustrates the implied ‘circular’ process of the hermeneutical approach. The ‘parts’ in the figure are referencing meanings that arise in the context of the ‘whole’ and the ‘whole’ is referencing the meaning of the interpreted ‘part’. All transcripts from this study were analysed following this process. The hermeneutical circle was repeated until all the transcript’s ‘parts’ and ‘whole’ were interpreted.

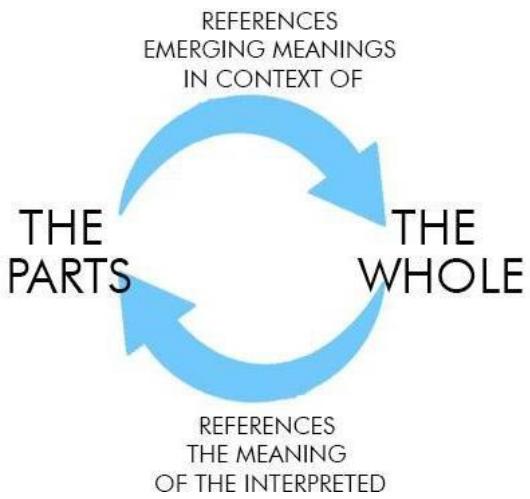


Figure 4.2.4c. The hermeneutic circle of participants' sense-making of the experience.

The next step in this analysis was the application of a double hermeneutic. This concept was proposed by Giddens (1982) to emphasise that social science researchers, in comparison to researchers in the natural sciences, need to analyse cautiously as there are two dimensions within the field that need to be considered when interpreting. The *first dimension* refers to the complexity of scientific constructs in the human sciences. Giddens (1982) argued that because humans have a bilateral relationship with the world (for example, knowledge transforms people and people transform knowledge), theory and concepts around human sciences are constantly changing and consequently researched using multiple approaches. This identified challenge indicates that people's dynamic and convoluted relationships must be interpreted attentively to understand the complexities of the investigated phenomenon (Marcus & Fischer, 2014). This is not the case with the natural sciences, since the aim there is to objectively understand the natural world from a one-way perspective. In other words, researchers from the natural sciences aim to understand a phenomenon from a one-way perspective since the phenomenon does not aim to understand the researchers.

The *second dimension* invokes attention to contextual information that could provide a holistic understanding of the participant's worldview. This means that researchers who study human behaviours need to inspect background information (for example, history, culture, and linguistics) to understand why humans' worldview is the way it is, how they make sense of their world, and how their world shapes their behaviour (Gadamer, 1976). To address the challenges mentioned from both dimensions, Giddens (1982) suggested analysing the phenomenon under investigation using the hermeneutic circle twice, hence the name double hermeneutics. He extended that following this approach individually for both dimensions equips a researcher with foundations to claim an objective perspective from a subjective experience. Smith et al. (2009, p. 3) explained that with double hermeneutics, "the researcher is trying to make sense of the participant trying to

make sense of their experiences". For example, in this research, the hermeneutic circle first analysed how a participant made sense of his/her experience with ATs and all emerged meanings were interpreted directly from his/her interview. Figure 4.2.4c above illustrates the rationale behind the first cycle and addresses the first dimension. Furthermore, to attempt an objective interpretation, the researcher needs to repeat the hermeneutic circle process but with a focus on understanding the way the participant made sense of his/her experience. Figure 4.2.4d references the steps from the second hermeneutic circle which deals with the challenges raised from the second dimension. Firstly, the researcher reassessed the 'parts' from the participant experience (namely, themes, diary entries, annotations, and contextual information). Then, she referenced the emerging meanings against her own preconceptions to avoid any bias. Lastly, the identified assumptions, guesses, or inferences about the participant's narrative were bracketed to refine the findings from the experience. This process continued until the researcher interpreted all the established contextual settings from the 'circle'. In this study, the identified contextual information included the historical, cultural, and linguistic elements that shaped the informal caregivers' experiences. The following section contains the results of the individual analysis of each participant.

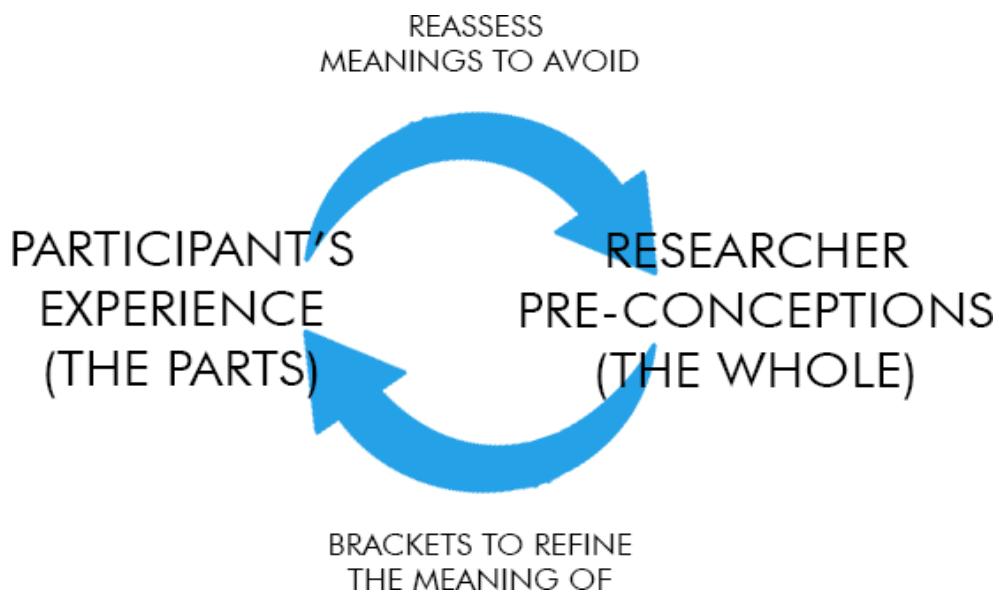


Figure 4.2.4d. The second cycle of hermeneutic circle analysis.

4.3 Results from the idiographic analysis

This section contains the results from the nine participants that were recruited from an Alzheimer's Association in a city in Mexico. The aim of the following interpretative accounts was for an in-depth understanding to be gained of participants' perceptions about ATs and the world. In addition, these accounts also include descriptive elements about the participants' lives based on the interactions the researcher documented in her personal diary after each interview and the participants' transcripts. As was pointed out in the previous section, each participant was analysed using an idiographic approach. This approach consisted of following a systematic procedure (section 4.2.3) that identified themes and placed them at two categorical levels (namely, superordinates and subordinates). In this study, superordinates are the high-level categorisation that clusters any themes with identified patterns (Smith et al., 2009). In contrast, subordinates are the low-level category of themes that belong in a group that share a commonality or are descriptive of an idea (Smith et al., 2009). To exemplify these statements, figure 4.3 illustrates these two-level categorisations. The toaster, blender, and microwave are positioned at the subordinates level since they share a commonality. The superordinate level in this example is kitchen appliances as it is a suitable name describing the apparent commonality among the aforementioned subordinates. All the themes that emerged from this research were interpreted using a double hermeneutic approach (described in section 4.2.4). Sections 4.3.1-4.3.9 contain the participant's accounts. Superordinate themes will be **emboldened** and subordinate themes will be presented with *italics*. Quotations, coloured in blue, will be used to explain participants' accounts and support interpretations. All names mentioned in the interviews have been changed intentionally. Lastly, section 4.4 concludes the chapter.

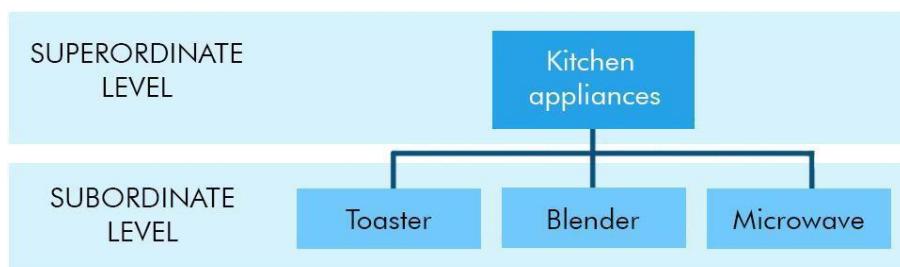


Figure 4.3. Two levels of categorisation

4.3.1 Sofia's account

Sofia was a full-time carer for her mother who was diagnosed with Alzheimer's disease more than 10 years ago. She struggled to **rationalise the diagnosis of dementia** for years. At some point during the interview, she was able to make sense of how she had been *denying the diagnosis of dementia*. She expressed this realisation by describing:

"She hid things, she repeated things and everything I attributed to her age, I thought that was part of being an elderly person. Then she started doing strange things, for example, she liked to put her shoes in the oven and I still justified it. I said, 'she probably likes them to be warm'" (Sofia, 487-490).

Sofia was trying to justify her mother's erratic behaviour with excuses (for example, it was a mistake, a little accident, a one-time thing) since she could not understand what was happening. After multiple visits to different doctors, her mother was diagnosed with dementia. The unfamiliarity with the disease made her *assimilation process* a very difficult one. She felt the need to educate herself about the condition since she became the primary caregiver for her mother. Sofia understood dementia as a structured and progressive disease. During the whole interview, she categorised dementia into stages:

"...at a certain stage of the disease... in another stage... it was at different stages..." (Sofia, 5-6, 8, 10).

Sofia's depiction of dementia was consistent with general public knowledge. However, through her discourse, it became apparent that she was a person with a need for information, at least, at an unconscious level. In this case, Sofia felt the need to inform herself about the topic to rationalise, process, and accept dementia. After learning the specifics of dementia, she used this knowledge to form her own ideas about the situation. The previous quote reflected how Sofia emphasised the word "stage" to describe what dementia means to her. Thus, she concatenated the knowledge she extracted from theory (that is, the categorisation of dementia by 'stages') and her own experiences (namely, the use of 'at a certain', 'in another', 'it was at different') to express her opinions about dementia.

Sofia has children and decided to move into her mother's home with her children to provide for the care and needs of both her children and her mother. Sofia's siblings imposed the role of carer on her as she lived at their mother's home. As a consequence, she developed negative **effects of caregiver burden** that made her feel that her life was collapsing.

"When things started to get complicated because of the dementia, I felt that I could not deal with the responsibility alone. They [siblings], thought that it was common sense that if I lived there, I would voluntarily take care of her [mother]. And things are not like that sometimes. It's hard to know about this disease and know how to react to it and the fact that no one helps you; it really gets to you. That made me feel bad because I did not like it; I did not want it for me or anyone. It was very difficult, very difficult for me to have had that big responsibility on me" (Sofia, 167-173).

The imposed role led her to experience caregiver burden since she had multiple responsibilities at that time (for example, being a caregiver, employee, and mother). Whilst caring for her mother, she was allowed to work remotely from her mother's home on a full-time basis. Although that arrangement allowed for some flexibility, she also had to care for her children, completing the everyday chores that any mother has. The combination of those activities brought increased costs, stress, and depression into her life. Sofia's role started to become problematic when she became completely immersed in her caregiver role, isolating herself from friends and wider family. She realised that what she was experiencing was depression, and she decided to go for a holiday with her children and hire full-time nurses to care for her mother while she was away. Nevertheless, she felt anxiety throughout the holiday. When reflecting on this event, she realised that it was because she was away from her mother for the first time since assuming the caregiving role. She believed that she had grown to become *codependent with her mother*. She recalled:

"A codependence is created. They need you but you are already too involved so that you cannot get out of that mess. Your life is immersed in that disease, so you neglect yourself. You do not want to know anything; you say no to everyone. I never said no to anything before and at that stage I did not go out with my friends. I left my hobbies; I left everything because I had to take care of her and that was my excuse" (Sofia, 571-576).

To Sofia, this codependency was rooted in her need to feel needed. At this point in her story, she was deeply committed to her role that she began to lose her identity pre-caring. She became obsessed with her family's approval so that any criticism or disapproval from her mother or siblings affected her self-esteem. Sofia needed validation from her caregiving role because she felt alienated from her family. Furthermore, when she returned from the trip she realised that her siblings had installed monitoring cameras inside her mother's home without her consent. Sofia saw this action as a breach of her and her children's privacy and demonstrated a lack of trust after caring for her mother for many years. Devastated, she continued with her caring role and distanced herself from her siblings. After that point, their relationship deteriorated. It gradually progressed from mistrust to a lack of support that she vocalised during the interview:

“...many other problems started between us [siblings], for example, us saying “it’s your turn, it’s not your turn” – which is something that I did not like” (Sofia, 204-205).

The tensions became apparent and frequent so that caring for their mother *troubled their sibling relationships*. Sofia felt torn at this point since she wanted to find the balance to be a good carer for her mother, a good sister to her siblings and a mother to her children. Finding herself incapable of making everyone happy, she decided to ask for professional help. She remembered the *psychological distress* that she went through at the time and how the disease affected her overall wellbeing:

“We [humans] are limited and as I say we also have lives and this disease drags you. Only one person gets the disease but you as a caregiver and all your family members are dragged into the disease too.” (Sofia, 455-457).

This statement encompassed the emotional pain that she felt during her experience. Sofia used the word ‘drag’ as a metaphor. This can be interpreted as her viewing her role as a tedious and tiresome task. This quote also suggested that, to Sofia, dementia is a slow life raider that implicitly forces all family members to get involved in the caregiving role. From visits to financial contributions, however big or small the help, dementia claimed the family’s attention. Her lived experiences and time made her build strong **emotional resilience** to cope with the stresses in her life. For instance, after she *accepted the need for external help*, she realised that her feelings and emotional state were only temporary. She realised that it was ‘ok’ to step back from her role to work on herself.

“I believed for a long time that I could do it alone. Later on, I realised that it is best to ask for help and it is best to know that we just cannot do it alone” (Sofia, 472-474).

It took Sofia many years and a lot of courage to finally stand up for herself and regain control of her own life. Sofia described that she fully recovered when she started to go back to church. She disclosed that she used her *faith as a coping mechanism*.

“I would advise everyone to hold onto God’s hand in order to cope with this disease that is very hard, but it can be done, with his help” (Sofia, 651-653).

To Sofia, faith represented hope and internal strength. The metaphor “hold on to God’s hand” symbolised Sofia’s constant need for patience to exercise her role. Religion gave her a designated system that helped her cope through the hardest times. This system consists of all the beliefs and practices that come with her particular affiliation. Moreover, during the interview, Sofia explained that the feeling of being constantly observed by her siblings made her self-conscious about her caring role. She expressed feeling overpowered by her siblings’ decision of placing the cameras, and felt the need to voice her **opinions about the technology**. Notwithstanding this, she shared that long before the placement of the cameras, she incorporated an old baby monitor for her caring role. Sofia bought this baby monitor and mentioned that it was the one she used when her children were toddlers. She appeared to be keen about the baby monitor as she explained the *benefits of the technology*, for example:

“I preferred when I had the [baby] monitor and could listen when she [mother] got up from her bed. The nights I did not hear her, I would open my eyes and there she was standing next to me and staring at me” (Sofia, 78-81)

The baby monitor helped her prevent nocturnal accidents and unwanted scares. With this statement, she was implying that this technology only served her personal needs as she was the only one using it. To her siblings the baby monitor provided no benefits, however, the monitoring cameras made them feel less guilty and gave them a sense of having an active caring role. As the disease progressed, Sofia became aware of how one of her siblings became increasingly obsessed with watching her mother through the camera. She attributed this behaviour to a *consequence of misusing the technology*.

“I believe that technology is a good tool that allows you to be able to continue with your life. But I also think that in the case of monitoring cameras, you have to know how to set limits, because as I told you, I felt that my sibling was obsessed [with watching mum]” (Sofia, 132-134).

Sofia’s opinions about the technology have been so far, positive. Notwithstanding, it appears that during her experience, she only adopted one AT (a baby monitor) and her siblings, another (monitoring cameras). These statements suggest that Sofia was cautious with her selection of ATs and developed a *techno-sceptic attitude*.

“Believe me, I was not 100% sure about placing cameras around the house because I feel that it is something that you can obsess about... Like watching how they [nurses] work and if they are doing their work to a certain standard” (Sofia, 40-41).

She only appropriated the AT that made her feel comfortable and that was not forced upon her. As previously stated, the cameras were installed by Sofia’s siblings without asking for her opinion.

Sofia took their decision as an offence and therefore direct aggression towards her caring skills. It can be interpreted that Sofia's perceived this AT as unnecessary since she believed her siblings purchased the cameras to give the illusion that they cared. Since she associated these cameras with a sour experience, she developed a scepticism towards cameras. Nevertheless, in spite of her unpleasant experience, she strongly believed that the **AT served as a source of accountability** during her time as a carer.

"The need to observe the care of my mother was covered [by cameras] and that relaxed the attention of my siblings over me. Because before, they knew about mum through what I said or through what the girls [nurses] said and that was a big problem for them. The girls had a version of things and I sometimes had another, which we discussed with the rest of the family, and sometimes things were different. So I think the cameras brought objectivity to what was really happening" (Sofia, 350-355).

This particular AT [camera] helped ease and solve confrontations with her siblings. To her, the surveillance camera provided evidence of the care. Her statement "*relaxed the attention of my siblings*" suggests she strongly believed that part of the felt burden was attributed to the criticism and questioning she withstood before the adoption of the surveillance cameras. Finally, Sofia did not regret any of her past decisions or actions and felt at peace with her choices. The combination of her opinions and previous experiences shaped her views about ATs. At the time of the interview, her mother resided in a nursing home due to her advanced Alzheimer's and she was bedridden at that time. Table 4.3.1.1 is a brief summary of the superordinates and subordinates that were identified for this account.

Superordinates	Subordinates
Rationalising the diagnosis of dementia	Denying the diagnosis of dementia
	Assimilation process
Effects of caregiver burden	Codependent of her mother
	Troubled their sibling relationships
	Psychological distress
Emotional Resilience	Accepted the need for external help
	Faith as a coping mechanism
Opinions about the technology	Benefits of the technology
	Consequence of misusing the technology
	Tecno-Sceptic attitude
AT served as a source of accountability	AT [camera] helped ease and solve confrontations
	Surveillance camera provided evidence of the care

Table 4.3.1.1 Summary of Sofia's idiographic analysis

Table 4.3.1.2, is a small sample from the analysis of Sofia's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.1.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 5: Sofia Time: 1:05 Total lines of transcript: 653					
Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Superordinate Themes
We used	Collective, sense of belonging to a group.	linguistic	5	Family as a system	
We used cameras at a certain stage of the disease where she was cared for by professionals... by professional caregivers and we felt the need to see how they were doing their work.	Used the cameras to monitor how the carers were doing their job, rather than to monitor their mother.	descriptive	5-7	Cameras used to monitor carers.	
...we felt the need to see how they were doing their work.	Need to control? Collective anxiety?	linguistic	7	Siblings did not trust nurses.	Troubled Sibling Relationships
...we used the baby monitor...	Who? She still refers to herself as part of a unit-family.	linguistic	8	Family as a unit	
...we used the baby monitor to know more or less at what time she woke up and not have to be literally next to her.	Used the baby monitor to learn mother's habits and her own convenience. This gave her some personal space and privacy.	descriptive	8-9	Technology allowed her some personal privacy.	Benefits of Technology
...at a certain stage of the disease...in another stage...it was at different stages	Acknowledges the disease has different stages and understands the different needs in each of them.	conceptual	5-6,8,10	Understands different stages of	Processing dementia

Table 4.3.1.2 Sample Data Analysis of Sofia

Reflective Box

Interviewing Sofia was somewhat difficult since she only offered me time for her interview at work and during working hours. This brought several complications that affected the quality of the interview since we were interrupted twice. Returning to the interview after each interruption was complicated as resuming the pace of the interview felt artificial and forced. To put it in perspective, the first interruption was three minutes where a colleague was asking for some information. The second interruption was 10 minutes in which she had to take a phone call. During that second time, I decided to leave her office so she could take the call privately. When I returned to her office, Sofia expressed how sorry she was for both interruptions and it was obvious, based on her tense gaze, that she wanted to finish the interview soon. For me, as an interviewer, this experience opened my eyes to the fact that I always have to be alert to this type of unforeseen event. Fortunately, I prepared myself well and at the moment when the interruptions happened, I wrote down the last question to prevent losing the conversation. To my surprise, I got the impression that after the second interruption, Sofia felt a little more comfortable with me and began to speak freely about her feelings. However, the change was drastic for me, since her emotions were quite difficult to interpret. For example:

"You learn to communicate in another language, which is the language of love" (Sofia, 643-649).

"I tell her that I have a doctorate in patience and that the doctorate has been given to me by the university of life. She has given it to me because this disease can only be cured with two things: with patience and love" (Sofia, 645-648).

As you can see, Sofia began using metaphors to express her emotions. This speaks of how difficult it was for her to open up about this vulnerable topic. From my point of view, her emotions were complex since Sofia was narrating something that she still had no time to process. That is, Sofia, at the time of the interview, was still actively in the role of her mother's caregiver and since this experience was her present, it was expected that her emotions would be intensified. Moreover, during Sofia's analysis, I had to read literature on vulnerability and the use of metaphors to understand her point of view. I also had to return multiple times to the recordings to pay attention to the tone of her voice used before and after the interruptions. I think this helped to reflect an interpretation closer to the true essence of Sofia.

Findings from Sofia's account

- Sofia used religion as a coping mechanism.
- The AT provided Sofia with a factual video that helped reduce conflicts.

Sofia used the AT only when the AT proved to be reliable.

4.3.2 Claudia's account

Claudia's father was diagnosed with vascular dementia, which arose as a result of a previous stroke. Claudia could not give me an exact date when the stroke occurred as she told me she had blocked out the painful memory. However, she estimated that her caregiver experience lasted around 15 years. Her father was primarily cared for at her home for a period of time. She constantly expressed how difficult the whole experience was for her as she felt pressure to meet the **cultural expectations** her siblings and friends were bestowing upon her. Claudia thought it was unfair the way her family handled the caring responsibilities. For instance, she started to realise, while narrating her story, that she instinctively knew that it was 'ok' for her to demand more participation from her sisters and address any issues with them. Whilst for her brothers, this would be an inappropriate request that would have been seen negatively by the extended family. As the interview progressed, she started to make sense of these events and the apparent *gender roles* that were instilled in her. She expressed:

"My brothers did not get involved at all. How convenient." (Claudia, 393).

This quote reflects the moment she realised her brothers' only caring responsibilities involved financial contributions. Claudia's brothers assumed the role of monetary providers. By undertaking this role, their brothers dissociated with the burdensome tasks of caregiving (for example, toileting, grooming, and so forth). This positionality is consistent with *machismo* behaviour (described in section 1.2.4), namely, alluding to 'manly' qualities such as being robust and brave, and playing the role of guardian and provider. Claudia's epiphany made her realise that she normalised her brothers' behaviours and wrongfully resented her sisters for years. This realisation suggests that she was clouded by her values and was incapable of rationalising, at that point, the unfairness of the situation. Claudia was dealing with many things on a personal and professional level, meaning that her caregiving role became overwhelming.

"I had to assume it [caregiving role] basically 100%. So, this... well, it was very difficult for me" (Claudia, 396-397).

Balancing her responsibilities as a wife, daughter, and mother drained her. At this point in the interview, Claudia acknowledged that her caregiving role was imposed as a consequence of the distance placed by her sisters' and brothers' disinterest. Her family's behaviour appeared to be careless and this increased her stress. Presumably, Claudia felt stressed because she voiced, on several occasions, the help that was needed and did not get it from the people who should be involved in the experience (namely, her siblings). As her awareness progressed throughout the interview, she acknowledged that one of the reasons why she continued to care for her father until his final days was out of loyalty to him. She reflected upon her role:

"Well, I believe in loyalty – being loyal to him after he took care of us. He always gave me everything; he was a good father. So for me, it was a way to repay him with the same favour – it was like a kind of love – out of loyalty to him" (Claudia, 406-408).

Loyalty in this context was interpreted as a symbol of respect that was influenced by the value of *familism*. As mentioned in section 1.2.4, familism is a value that enhances the importance of loyalty, honour and dedication to one's own family. Claudia wanted to wholeheartedly honour her father and help him. However, the forged resentment against her siblings made her experience **caregiver burden**, affecting her entire persona.

"To me yes, it was a really difficult situation. But.... what can you do? The only feasible thing was to go on at the cost of my health, my family, and my children because I tried to help him" (Claudia, 379-381).

"It was very tiring and I did see it as a duty because who else would have done it?" (Claudia, 412).

Claudia's quotes confirm the lack of involvement from her siblings with their father's care. Two key expressions suggest that she felt unaccompanied and unaided during her experience "*what can you do?*" from the first quote and "*who else would have done it?*" from the second one. These emotionally charged expressions suggest that Claudia is implicitly blaming her siblings for all the hardships she went through. This is presumed because the only other people that could have assumed the caregiving responsibility were her siblings who were clearly avoiding the role.

"My siblings were upset because I have the tendency to test them [their loyalty to father]. I said to them: "Yes, I was testing you all, because I wanted to see what you were capable of doing for dad. And I tell you all beforehand that you are going to care for dad too, because it is also your obligation. And whoever does not comply, I'm going to report you [authorities], because you are not doing your job as his children." (Claudia, 390-396)

She was desperate to find a solution to her *overwhelming role* since anxiety was progressively becoming a regular incidence in her daily life, as was exhaustion. The previous quote, shows how her emotions made her *irritable and confrontational* around people, in particularly her siblings. Furthermore, Claudia remembered how vulnerable and isolated she felt at that time.

"I had to use my personal resources to more or less cope with situations" (Claudia, 188).

In this context, personal resources were interpreted as Claudia's personal money, skills, and knowledge. Claudia's statement suggests she found it difficult to trust others since she believed in her self-efficacy. To her, being her father's caregiver was a lonely and alienating experience. She recalled:

"Well, I had to [assume the role of caregiver]. I had to put up with it [since siblings were not helping]. I only saw my dad, my husband and children during that time [caregiving experience]." (213).

Claudia found it difficult to open up (to the researcher) and share how she struggled during her time as a caregiver. During the interview, it was evident by her body language that she felt embarrassed to admit she felt alone during her time as a carer. Moreover, it can be seen that Claudia continued her statement hesitating when she revealed her family's lack of support. She stumbled with her words with evident pauses:

"That's right [pauses] – no, no, I did not have it [family support]" (215).

Her hesitation implies that she felt guilty when speaking negatively about her family, since after all, in the present time she mentioned (in the interview) being in good terms with her siblings. However, during her caregiving experience, believing that she did not have any support increased her perception of caregiver burden. This formed idea of emotional abandonment triggered unfavourable **attitudinal changes** that affected not only her but her entire family. It took her years to find emotional stability after the experience. She was able to open up about the struggles her caregiving experience had on her marriage. For instance, she described how she increasingly started to speak rudely to her husband. Claudia started to take for granted her husband's support by becoming *highly domineering*.

"I would say to him [husband] 'Run, go and buy medicine and nappies. Then come back and help me with this'" (Claudia, 251).

Claudia admitted that she relied heavily on her husband during her time as a carer. Her imposing demands progressively affected their marriage. Claudia's unmeasured demands could be rooted in the lack of help from her family. She felt that without delegating tasks, she would not have been able to survive the experience. Since her husband was her only reliable ally, she wanted to demand of him the duties that were her siblings. However, Claudia could not see how the responsibility only belonged to her and her father's family. Another attitudinal change was Claudia's increasing *need to control* people and situations. For example, when asked about what would be the ideal technology for her caring role and why, she responded:

"A device that can monitor the arrival and departure of a nurse" (Claudia, 328-329).

"It could be a portable camera that would be worn by the nurse or... I do not know, for when a nurse is with him [patient]. This will allow... to see what they [nurses] are doing or how he [patient] is doing. I would like to see his face, his body, or his reactions. I would like the nurse to have it [camera] around her neck or in a backpack, on a clip, or something. So, like a 360-degree portable camera with night vision, with obvious daytime vision, with audio... and... so that you can also be there [with them]" (Claudia, 333-339).

Her statements suggested that she wanted an AT only to observe the nurses, not her father. This was a conflicting view since one would expect that the caregiver would describe their ideal technology for their role as being something that would benefit the patient. Claudia's statements also implied a lack of trust in the nurses. One could argue that her mistrust stemmed from her siblings' unreliability with their father's care. She suspected her siblings alienated her to avoid responsibilities, making her more apprehensive with control. Therefore, Claudia could have been thinking that if her own family was not giving or doing much for the wellbeing of their father, neither would the nurses. Another interpretation for her statements could be that she wanted an AT that would allow her to provide and manage all caring responsibilities online. Claudia's expressions "*to see his face, his body, or his reactions*" and "*you can also be there*" suggested that she still wanted to participate in the experience but keep a distance. To a certain extent, it appeared she wanted to avoid burdensome tasks and rely on an AT that could provide her with the surveillance that permits interaction with the patient. Claudia was advised by a close friend to get a surveillance camera. She hesitated as she described herself as a **technologically insecure** person. After multiple episodes of her father leaving her house, her husband installed a black and white camera and audio recording devices to track him down. Since this was many years ago, cameras were not as advanced as they are now and it did not include audio and colour video. Claudia described herself as someone *inexperienced with technology*. She was worried that she could not handle the new adopted AT and as a consequence she only had *partial trust in the technology*. Claudia described the **positive effects of having an AT** for her role.

"I felt comfortable being able to see him [father] even though I was not there because I was working. So before having the camera, I was anxious all day wanting to hear from him, observe him, and care for him" (Claudia, 174-176).

This statement suggested that the AT helped her *decreased her anxiety*. She expressed how stressed she used to feel at work thinking about her father. It was understandable that Claudia felt anxious when being apart from her father because she knew the many ways that he could get hurt or that he would require assistance in performing daily activities. Since she adopted the AT she was able to *balance work and caring duties*. Claudia felt in control of her life once again.

Furthermore, Claudia became aware of the need of a person to fulfil the remaining caregiving duties (for example, feeding). She decided to hire a part-time nurse to help her with her father. As she did not trust her, she recorded the conversations between the nurse and her father to prevent any abuse. This was done without the nurse's consent. When she realised that she could not continue with this role, she took her father to a nursing home where he passed away a year and a half later. Table 4.3.2.1 illustrates the superordinates and subordinates from Claudia's account.

Superordinates	Subordinates
Cultural expectations	Gender roles
	Machismo
	Familism
Caregiver burden	Overwhelming role
	Exhaustion
	Irritable and confrontational
Attitudinal changes	Highly domineering
	Need to control
Technologically insecure	Inexperienced with technology
	Partial trust in technology
Positive effects of having an AT	Decreased anxiety
	Balance work and caring duties.

Table 4.3.2.1. Summary of Claudia's idiographic analysis

Table 4.3.2.2, is a small sample from the analysis of Claudia's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.2.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 7 Time: 29:28:00 Total lines of transcript: 458					
Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Superordinate Themes
What we used specifically was a portable voice recorder. I came up with this resource because of a family need we had at that time. We used it and then hide it to record secretly. That is what I basically used and also a video camera.	She wanted to surveille her father. She recorded audio without people's consent to hear conversations. Does she have controlling problems? Also she first says they all used the technology and then that only her.	descriptive	4-7	Need to control	Controlling behaviour
A visual camera and you could enter a webpage on the internet, put a password and as I could, at times, I watched my dad.	It is difficult for her to describe how the technology worked. It was a vague description.	descriptive	8-10	Inexperienced with technology	Technologically insecure
When I bought it...	She is taking the credit of the idea and purchase of the technology. Does she want recognition from her family?	linguistic	17	Seeks validation	Low self-esteem
I put it...WE put it [technology]...	She hesitated when she realised that she was taking all the credit for the idea. Why?	linguistic	18	Self-aware of her words	
It had no audio. It was kind of rudimentary. So then ... when I bought it, it was just a monitoring camera that was	She describes the technology as something antique, that would be considered outdated in the present time. Also as something that has many	descriptive	16-19	Downplay's technology	

Table 4.3.2.2. Sample Data Analysis from Claudia

Reflexivity Box

This interview was a challenge for me because Claudia had the tendency to respond with short answers. This interview was conducted at home and fortunately, there was no time restriction. The first impression that Claudia gave me was of a person who was a little distracted because when I arrived at her house, she was very surprised. She had the impression that the interview was going to be another day. Consequently, I could feel that there was tension in the room when she started talking about her experience as a caregiver because she had not prepared for the interview. I noticed that during the interview she struggled to remember details about her father's condition. She repeatedly answered:

"I have no idea" (Claudia, 260).

"I don't know. I am telling you the truth, I can't remember many things" (Claudia, 264-265).

"There were a thousand things going on in my life at that time that I can't remember" (Claudia, 386-387).

This detail worried me because when she was trying to remember, I could see her frown constantly. Seeing how she was reacting with tension and shortening her answers, I realised that I was making a mistake. My questions were closed and therefore, Claudia could not express herself freely. This was a humbling experience for me because I realised that it was me who was making the participant feel restricted. To compensate for this mistake, the rest of the questions were open-ended allowing me to gradually extract the necessary information as the interview continued. Finally, at the time of the analysis, I had to first accept my mistake and remember that my perception of Claudia was being directly affected by the type of questions I asked. So I had to go back to the recordings to focus on the tone of her voice and response times. Having these elements in mind whilst reading the transcript made me unravel a different Claudia beyond the texts.

Findings from Claudia's account

- Claudia's cultural values influenced her caregiving style.
- The combination of many responsibilities (i.e., being a mother, carer and employee) increased her caregiver burden.
- The value of familism was the reason she took the role of caregiver.
- Claudia's caregiver's burden increased as a consequence of her family's lack of support.
- The use of ATs decreased her feelings of anxiety.
- The AT reduced Claudia's caregiver burden but did not remove her need for a physically present caregiver.

4.3.3 María's account

Maria became her father's primary caregiver after he was diagnosed with dementia. All her siblings decided that it was best for their father to live in his own house. In order to make that work, they made her father's home suitable with the help of an architect to address his new needs. On the ground floor, the architect built a replica of their father's bedroom to make him feel comfortable in his surroundings. Maria visited daily and stayed there all day, as much as she could. At night, she returned to her own home and spent time with her children. **Processing dementia** was a very difficult task as she claimed her father was a healthy and active man.

"Everything was so sudden, out of nowhere" (Maria, 299)

"I think that because he [father] was so responsible [during his life], he suddenly disconnected from the world... I do not know. I do not really know what happens with this disease" (Maria, 401-402).

To María, *making sense of the diagnosis* was challenging because she could not understand what triggered the disease. She was not expecting the diagnosis as she never saw any early signs or symptoms. Her father's rapid health deterioration overwhelmed her and all her siblings. She was trying to find answers and to connect the dots of her father's past and habits to rationalise the situation. As time went by, she developed *negative feelings about the disease* that led her to have emotional reactions that complicated her experience. For example, she described her disbelief after witnessing how her father was progressively changing his behaviour as a consequence of the medicines he was prescribed.

"And they changed his medicine and they suspended one and they changed to another and I saw VERY, VERY, VERY awful behaviours and I was in disbelief. It was nothing like him. No, it was not him. It was a TERRIBLE thing. I was scared, scared – you know what I mean? Because I said to myself, "what happened to my dad?" (Maria, 223-226).

Maria had a mixture of negative feelings that ranged from disbelief, distress, confusion, anger and frustration. This particular quote was full of emotionally charged expressions. The capital letters represent the exaggerated language she used to emphasise the emotionally painful experience. The words 'very' and 'terrible' were being exaggerated purposively to stress the fear she had of losing her father to dementia. However, María did not intend to be taken literally. From an objective point of view, her father had different behaviours that seemed unacceptable to María, but to the medical community, they were normal dementia-related behaviours. Hence, María's emotionally charged statements were a way to dramatise her lived experience. She was scared of how the disease was changing her father, but she was also scared of the complications of the disease that

would occur in the near future.

Furthermore, Maria was directly influenced by **instilled cultural roles** and traditions that shaped her decisions and actions. For instance, she was very open about the fact that she took the role of caregiver because she felt that it was her duty.

"I am the one who called the shots and I am the one who talked to the doctor (snapping her fingers)... I made the decisions at critical moments" (Maria, 236, 238).

"I was a thousand times closer to my dad than to my mum. That's the truth. My dad understood me... a lot. It was like we were speaking the same language" (Maria, 226-227).

Maria was the eldest of her siblings and a natural leader. Her leadership skills helped to direct her siblings throughout the experience. Maria snapping her fingers can be interpreted as her having high self-esteem and self-confidence. In addition, her self-sacrificing act as a carer could be interpreted as the embedded value of *familism*, in which family is prioritised above anything else. In the second quote, Maria stated that her father and her spoke the same language. This expression represented the closeness of their relationship. She felt the need to care for her father because she could not accept losing him to dementia. Another example of culture's influence on her was the *normalisation of traditional gender roles*.

"Dad was directly taken care of by the three women [sisters] and the men [brothers] accepted and respected any of our decisions [about care]. We just informed them when it was needed. When there was a need to participate with money, then that was the time that they [brothers] contributed but we [sisters] always took care of things; we never asked them [brothers] – that's the truth [laughs]" (Maria, 54-58).

Maria did not see anything wrong with her brothers' lack of participation and their role as providers of financial support. To her, it was normal that women acted as carers and men as providers. Her relaxed attitude towards gender roles suggests that Maria was brought up with these stereotypes. Seeing this example at home could explain why she normalised this categorisation. Maria also explained how she used her *spirituality* as a coping mechanism.

"I used to grab onto a rosary and pray 'please, please, please my God'. I would never complain – 'why did you allow this God?' – never! I never had that attitude. I always had it very clear – that it is not God who commands these things; it is bad people who do this. God cannot allow these things, they just happen, but I used to pray to God many times. 'My God, if this happens, I ask you please, do not let go, do not let go of me', and it was like that" (Maria, 502-507).

"My faith is what helped me during that [caregiving] time, there is no other explanation, really. I can't explain it [divine force]" (Maria, 533-534).

Maria's Catholic faith was used as a way to alleviate the stress of caregiving. The previous quote reflected the importance she placed in her spirituality and how it became her coping mechanism. She regularly prayed for guidance and inner strength. It appeared that Maria was using her religious beliefs to make sense of dementia. The second quote suggested she believed that her faith, namely, a divine force, provided her with the inner strength to endure the hardships of caregiving. As her father's dementia progressed, Maria's siblings hired a full-time nurse that helped during the hours that she could not be at her father's home. After a year, the family noticed bruises on their father's body and a quick decline in his health. The family could not find a reasonable explanation and decided to place hidden cameras inside their father's room. Her case was a clear example of how by **appropriating technologies**, people can meet their technological needs by adapting it to their daily lives. The implemented cameras were missing one particular need that her family, which was a need for audio recording. She then explained how she covered that need.

"A little voice recorder – a little one that my husband gave me. It was one of those for office use and then I went in just like a detective to hide them" (Maria, 130-132).

Since Maria's cameras had no audio, she proactively *implemented a surveillance system*. This system was sufficient for the family's specific needs and was "*rudimentary*" (Maria, 14). Notwithstanding, the *improvised use of technologies* demonstrated how Maria, with her limited resources, appropriated the technologies to fit her requirements. This new system allowed Maria to monitor her father and the hired nurse in a convenient way. With this in mind, Maria was then able to evaluate the quality of the nurse's care. One day, she was reviewing some audio recordings and noticed how the nurse was mistreating her father. She then had to manually match all the audio recordings to the video recordings that included the nurse to verify the potential elderly abuse. The emergent footage was confirmation of the abuse and the nurse was fired. This situation infuriated her and the wider family. As a consequence, she started to develop **effects of the caregiving role**. The most evident effect was that Maria *developed mental distress*.

"I wanted to jump out of the window – horrible, horrible, horrible. And at that time I thought, 'you know what? I need help, I don't know what's happening to me'" (Maria, 582-583).

"I was fine, until one day, I do not remember at what moment, another panic attack was about to happen to me in the middle of a store and I said to myself, 'you know what? I am fed up of this, I cannot do it alone. I need psychiatric help'" (Maria, 597-600).

Maria could not comprehend the root of her progressively recurrent panic attacks. Through her statements, it could be implied that her anxiety was becoming difficult to control and was affecting many areas of her life (for example, her physical health and personal relationships). The use of the word '*horrible*' multiple times and tone of her voice (during the interview) suggests Maria felt anxious about remembering that moment. She then explained how she was able to regain control of her emotions:

"Then, I began with a therapeutic treatment. I went to therapy, I had medication, well, antidepressants. They [doctors] told me I had panic attacks as a consequence of an [chemical] imbalance." (Maria, 600-602).

The previous quote implies Maria's willingness to get better and sort her mental health. By addressing this issue, she was able to prevent any future panic attacks. Another effect of her caregiving role was Maria's *confrontational attitude*.

"Of course I had intense confrontations with one of my sisters [youngest one], right? (imitating sisters voice) "Why if I want it that way?" I usually answered her: "You want that? Well, come and take care of him yourself. Don't bother me. I mean, do you want things done your way? Then come. I try to do my best." Of course, we stopped talking for a while" (Maria, 453-456).

This new behaviour strained many of her close relationships, including those with family members. Maria's confrontational attitude was a reaction to the increasing levels of stress and burnout she experienced with the progression of her father's dementia. Two years into her role, she was not able to care for her father anymore for personal reasons. Throughout her interview, she told of the events that led to the decline in her father's health and how her siblings worked around the situation. The caregiving experience affected the way she thought, acted, and felt about her father and surroundings. Maria disclosed that she *feared developing dementia*.

"I saw myself reflected in his [father's] state, I thought I was going to end up like him. I used to say, "Damn, I could end up like him!"" (Maria, 390-391).

This fear started when Maria's medical doctor explained that she could be carrying the gene associated with her father's type of dementia. This possibility made her change many habits that popular culture has pinpointed as being preventative measures for cognitive decline (for example, knitting, crosswords, and so on). Maria's expression '*I saw myself reflected in his state*' was her wake up call to change her bad habits and unresolved personal issues. She was determined to avoid the same pain for her children. This urge for change reflects how much the caregiving experience affected her life and the people around her. Table 4.3.3.1 provides a summary of the superordinates and subordinates that were identified for this account.

Superordinates	Subordinates
Processing dementia	Making sense of the diagnosis
	Negative feelings about the disease
Instilled cultural roles	Familism
	Normalisation of traditional gender roles
	Spirituality
Appropriating technologies	Implemented a surveillance system
	Improvised use of technologies
Effects of the caregiving role	Developed mental distress
	Confrontational attitude
	Feared developing dementia

Table 4.3.3.1 Summary of Maria's idiographic analysis

Table 4.3.3.2, is a small sample from the analysis of Maria's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.3.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Codes	Emergent Themes
Look, instead of using it to check my dad, it was to check the caregivers. To see if they were doing their job.	Used cameras because they did not trust nurses. Family distrusted nurses/carers.	descriptive	4-5	Distrust.	
They were monitoring cameras that were installed in the house and we could see what he was doing through the computer screens. What they[carers] were doing, if they took care of my dad.	Technology for monitoring purposes. Suspected that carers/nurses were not caring well for their father. Technology used to monitor the nurses/carers rather than father.	descriptive	5-7	Technology to monitor nurses/carers.	Need for detection/preventative technologies
And you could not hear it, then there is a point where you were interested to hear what was being said, how they were speaking to him. So we used voice recorders, little ones, that we hide as if we were detectives and then we realised what was really happening.	Cameras did not replace or reduce the need for caregiving. Technology did not suffice all of their technological needs. Didn't trust staff so decided to spy on them without their consent.	descriptive	9-10	Inadequate choice of technology	Indifference to technology
He needed 24 hour care and those cameras did not have sound because they were very rudimentary.	As they needed to hear and technology was limited, they improvised with other equipment. Spontaneity?	conceptual	11-14	Improvised use of technology.	
Well, my father was treated very	Technology helps them see how her	descriptive	14-15	Technology	Need for

Table 4.3.3.2. Sample Data Analysis from Maria

Reflective Box

Maria's interview was very conflicting. I say this because Maria and I had an impressive chemistry that was reflected in the quality of the interview. However, there were very difficult moments because the story of Maria resonated in me because of her pain. While she narrated her experience with great emotion, she was often in tears. Maria's pain was very transparent and palpable to me; there were moments when I could not control myself and I shed tears with her. I felt very embarrassed about this situation because I thought she might see it as a lack of professionalism. On the contrary, Maria was grateful for my humanity. Maria had the ability to make you feel like a lifelong friend. I feel that the level of connection I had with Maria was the most intimate and vulnerable in comparison to my other participants. For this reason, when analysing her interview, I had to focus on preventing my emotions clouding my judgment. I had to bracket, many times, the empathy I felt for her. For Maria's case, I had to visualise different scenarios. For example, I tried to see Maria's story without the traumatic events she went through. I did this to test my empathy because I wanted to know if it developed as a result of her story or if it existed because of the compatibility that Maria and I had. Furthermore, another angle to consider during the analysis was to remember if previous events before the time of the interview had influenced my mood (for example, was I having a good day, was there nice weather, was I annoyed by traffic, and so forth). In the same vein, I considered the emotional state I was in the day I analysed her interview. The different lenses through which I analysed her case helped me build a more objective account of Maria. In retrospect, I see how the experience I had with her affected the way I conducted the following interviews since it was the moment where I saw the importance of establishing rapport. I was concentrating on asking open-ended questions that would allow the participant to express their emotions. Not only did it have the benefit of opening the window of trust between the participant and me, it also allowed me to have a better understanding of the feelings participants were experiencing during their experience.

Findings from Maria's account

The following are the key findings based on Maria's account.

- Maria used her religion as a coping mechanism.
- Maria used the ATs to covertly record the interactions between her father (i.e., person with dementia) and hired nurse.
- The suspicion of elderly abuse was the reason that drove Maria to acquire an AT.
- Maria normalised gender roles within the context of caregiving.
- Appropriation of technology occurs when an unmet need is discovered.

4.3.4 Frida's account

Frida was a bubbly, warm, and chatty informal caregiver. With her great personality and sense of humour, the interview felt like an informal chat. Her mother was diagnosed with early-onset Alzheimer's disease two years prior to the interview, with her condition steadily worsening. Frida's mother was a widow, and since her husband's passing more than 20 years ago, she had lived by herself. Her family wanted their mother to live an independent life in her own home as long as the disease progression permitted. To comply with this, Frida installed cameras to monitor her mother and to allow her siblings who were abroad to observe her mother's progression. These cameras transmitted real-time video to Frida's mobile phone and had the capacity of storing all recorded material onto a server. Shortly after the system was implemented, Frida's mother's health deteriorated rapidly, making it no longer possible for her to live by herself. Frida's mother had trouble adapting to this new lifestyle. She found it difficult having someone at her home 24 hours a day, which triggered aggressive mood swings. Being the eldest of her siblings, Frida volunteered for the role of primary caregiver since she felt it was her duty. Frida had two sisters and one brother. All her siblings contributed equally to monthly financial support for their mother's needs. At this point, Frida worked part-time during the morning and she also hired a nurse to help her in her caring role from time to time, particularly for the night shifts. Frida explained how at her age it was difficult to care for someone else all day since this role required constant movement (such as walking up and down the stairs) and talking with her mother. She came from a supportive close-knit family that knew how to communicate and deal with issues around their mother. The heavy **influence of her family** shaped the way decisions were made for her mother. Notwithstanding, it was clear that Frida trusted her siblings completely. Hence, communication and organisation amongst all of them made Frida's caregiving role uncomplicated.

"And they [siblings] know that whoever makes the decision at the moment [of an emergency] is looking after the welfare of our mum. No one will ever do something that could harm her. We all support each other" (Frida, 625-627).

Frida not only thought her family was helpful, she also trusted her siblings' judgement. The *healthy relationship with her family* made her feel supported and protected in case of any emergency or accident. In the previous quote, Frida stated that her family worked as a team. In fact, she revealed that her sisters helped her regularly with caring duties. In the same vein, throughout Frida's interview, she explained and described her experiences using plural forms. For example,

“We had them...” (Frida, 14).

“We worry about mum” (Frida, 25).

“The cameras have helped us a lot” (Frida, 73).

“It has made life a lot easier for us...” (Frida, 315).

...to be watchful of our mother” (Frida, 227).

This could be interpreted as Frida's sense of belonging in her family. The constant use of first-person pronouns to refer to her family suggested that she thought they were all working together as a unit (a team). All her siblings appeared to show an interest in their mother's wellbeing. The sense of belonging made her feel like she was not alone in this experience and that she could count on more than one person in times of trouble. However, if Frida ever needed face-to-face help with any of her mother's caring needs, she could only rely on her sisters. The reason for this in Frida's case was because her brother's only form of support was being a financial provider.

“Well, he's [brother] at work all day, right? But he does not take care of either the doctor's appointments or the medicines because when the doctor arrives or is needed, he is not there on time” (Frida, 408-409).

“One of my sisters is in charge of buying diapers, wet wipes, and so on. Another of my sisters takes care of the bills. And I'm in charge of the doctor's appointments and medications. We have split the responsibilities” (Frida, 402-404).

“Well... maybe someone does a little less [participation], but nothing out of the ordinary” (Frida, 294).

These statements suggested that Frida recognised that her brother's involvement with their mother's care was minimal. Frida appeared to be a cautious woman that thinks before she speaks to avoid conflicts. This was made apparent in the interview through the subtle way she implied that her brother was participating less. Instead of saying it directly, she seemed to keep it implicit to avoid drawing attention to the matter. In her first quote, she appeared to justify the reason why her brother did not participate in the caring duties. Her expression “*he's at work all day*” seemed like a reasonable explanation of her brother's lack of involvement. Nevertheless, this justification came into question with her second and third statements which suggested that all her sisters had a dynamic role and “*someone does a little less*”. It could be deduced that she was referring to her brother as this ‘someone’ because evidently, he was the only sibling without a dynamic role (namely, that required moving, buying, and so forth). Her subtle hint indicated her conformity with this unspoken caring arrangement. Frida felt at peace with normalising the *implicit gender roles* in her family since adhering to that dynamic kept her family functioning. This could be assumed from Frida's account because she did not mention any quarrels or confrontations with her siblings. On the contrary, she talked about pleasant experiences with them. Moreover, Frida detailed how

she felt different **emotional reactions after the diagnosis**. Frida disclosed that she had no experience or training on caring prior to her mother's health decline. For Frida and her siblings, adapting to her mother's growing needs was a huge challenge. She described how scared they felt whenever their mother wanted to go outside. For example, Frida shared the ways in which her mother's urge to wander became an increasingly difficult task since her mother reacted aggressively.

"We [siblings] had to put plastic films on the windows. We placed them on the inside because she went and hit the windows. We were afraid she would break the windows and hurt herself" (Frida, 88-89).

"We [siblings] locked the door with a key because she [mother] wanted to leave and we were afraid that at a certain moment she would wander into the street. One day she was very aggressive, opened the window and began screaming "they want to kill me, they want to kill me" (Frida, 99-101).

These quotes described how Frida's family felt compelled to modify their mother's home and enforce new habits to prevent future accidents. Frida explained that she became *overprotective of her mother* when she realised the many dangerous situations that could occur because of wandering. The first implemented habit was to lock her mother's bedroom with a key at all times, even if someone was inside with her. She achieved this by having installed a deadbolt in her mother's bedroom. This type of lock can only be opened with a key. Frida explained how this measure permitted her to sleep through the night in the same room since her mother consistently tried to escape the room silently. The second preventative measure pertained to their mother's safety around windows. It was explained in the above quote how the family used plastic films to prevent their mother from hitting them and hurting herself. Eventually, they realised that the plastic film was not a long-term solution since their mother easily found a way around it and tore them down. As a consequence, Frida decided to make a third safeguarding measure. This time, all of Frida's nuclear family decided to hire an architect to make her living space adequate for her rapidly changing needs. The home improvement consisted in changing the entire ground floor to a one-bedroomed flat. Frida's nuclear family decided to keep this a secret to prevent any difficult conversations with the extended family and close friends. However, this did not last long because the hired nurse spoke of the new home adaptations during a casual telephone call with Frida's aunt. According to Frida, this happened when the nurse answered the phone and could not transfer the call to any other family member at that time. Since Frida's aunt was unable to speak with anyone else, she decided to directly ask the nurse about her sister's health. The nurse then provided detailed information that she was beforehand instructed not to disclose to anyone except Frida and her siblings. As a consequence, Frida's aunt learnt of the new living arrangements and was opposed to them. In fact, her aunt accused Frida of keeping her sister (namely, Frida's mother) a prisoner. She described the way she responded to her aunt's accusations:

"...we're not locking her in a room. In other words, she has a living room, dining room, kitchen, and the bedroom, and the door to the garden, which has fruit trees. So, she is not a prisoner in a room. It's not like I'm going to lock her in a room and here she's going to stay forever. Of course not" (Frida, 1051-1054).

Frida developed *defensive behaviour* after the emotionally charged confrontation with her aunt. The revelation of Frida's family secret brought unwanted attention, difficult conversations, and insults from the wider family. In this context, Frida and her siblings' decisions regarding their mother's care turned into a family secret after they chose to handle the living arrangements in secrecy rather than just referring to it as a private family matter. It could be suggested that Frida knew that if an accident were to happen under her care, her family and friends could blame her directly. In addition, she realised that if any of her care-related decisions somehow affected her mother's health, she would be held accountable. Frida feared that her caring style could be judged as negligent and harmful to her own mother. She voiced this fear in the following statement.

"You want to protect her from being lost, from crossing in the middle of the street. You know what I mean? So you feel like you are doing something wrong, but you do it because you don't want her to get hurt" (Frida, 981-982).

Her statement "you feel like you are doing something wrong" suggested that she feared that any of her care decisions, despite being made with rightful intentions, could be perceived as malevolent when an unforeseen or unanticipated circumstance affected her mother's wellbeing. Frida believed that by keeping any major caregiving decisions a secret from the extended family (uncles, aunts, cousins, and so forth), it would protect her nuclear family (siblings) from any blame or judgement. The confrontation she had with her aunt affected her deeply on a personal level. Thus, unable to accept any wrongdoing she unknowingly turned her frustration on the nurse.

"I told her "look, here it is like a hospital. Have you worked in a hospital?". She replied, "yes". [Frida continued] "Well, this is like in the hospital. So, when in the hospital someone comes to visit a patient and asks about their medical record, do you tell this information to anyone? Or who do you inform? [Nurse responded] "Only to family members and doctors". So I was making it clear that she has to tell things about my mother to both myself and my siblings. [Frida continued] "All those things you told my aunt, I heard them too. You do not have permission to speak to my aunt. You can only speak to us five [siblings]" (Frida, 382-390).

In her hurting, Frida patronised the nurse. This could be observed in the first quotation in which Frida reprimanded the nurse with a condescending attitude. For example, some of the first statements were interrogative (for example, have you worked in a hospital?). Her continuous interrogation corroborated the patronising behaviour. Frida's quote continued with imperative sentences commanding the nurse (for example, you do not have permission to talk to my aunt). This confrontation could be interpreted as Frida asserting her hierarchical position of power since the nurse was her employee. Moreover, Frida explained how difficult it was to **assimilate the diagnosis** since it changed her entire life routine and priorities. For instance, she talked about how upset she felt when receiving the diagnosis at the doctor's surgery.

"I said to him [the doctor] that there was no foundation in his diagnosis – it was not like a test. He only asked five questions, which are very easy to fail. For example, if I say five words and I distract you from the subject, I am sure that when I ask you to repeat the five words, you will not guess them correctly! You understand me? But your mind is already somewhere else or at least that's my experience. How can you possibly diagnose Alzheimer's from that?" (Frida, 936-941).

Frida's bitter reaction to the doctor's diagnosis disclosure was a form of *denial*. She reacted with denial to the diagnosis because it helped her cope with the unpleasant news. Frida explained that after she accepted her mother's fate, she felt uncontrollably sad.

"I sometimes leave her [mother's] house with a big smile. Then I go to my car, start the engine and drive to the next block to cry, to vent. Once I feel better, I drive back home" (Frida, 297-299).

"You are seeing how she is deteriorating because she was an active person before, like unstoppable... and... and now you are seeing her physical and mental deterioration [starts crying]" (Frida, 304-306)

These statements described reactions that are normally associated with *anticipatory grief* (see section 2.3.2), namely, the stages and/or feelings of grief that a person goes through prior to an actual loss. It appeared that Frida's uncontrollable feelings were an attempt to prepare her for the moment of her mother's death. Her bereavement was then interpreted as the confirmation that she had accepted the diagnosis of dementia and its consequences. Furthermore, when the researcher asked Frida if she felt caregiver burden during her experience, she outright denied it. When asked about her thoughts and the perceived benefits of using assistive technology for her caring role, she responded:

"...it [surveillance cameras] has made life a lot easier for us [family] because we don't need to check up on her [mother] all the time, right?" (Frida, 315-316).

"Well, knowing that you are watching her, that there is not one single event that you can miss now" (Frida, 331-332).

All comments made by Frida about the AT were fairly positive. She also disclosed that up until the time of the interview, the AT had worked perfectly for her family and brought positive experiences into their caring story. Frida had never experienced any problems with the cameras and she kept on referring to how the **technology served as an assistant** to her caring role. For example, she explained how the *technology helped her preserve memories* of her mother for posterity.

"So like I said, you can rewind it and record it... record the moment. I started to record the moments she [mother] danced with me. I want to keep these videos, because they are the last ones [of her mother], you know what I mean?" (Frida, 253-256).

For Frida, it was important that her AT allowed her to safely store videos of her mother since she wanted to keep them as memories. She also shared that the *technology was used to assist the nurse* when there was an emergency or unforeseen event. She explained:

"And then the stage of aggressiveness began. Whenever it happened, the nurse phoned me saying "Ma'am, your mother is very aggressive". And then, while on the phone with my mum, I tried to calm her down by saying "Mummy, calm down. Look, go to the room. Mum...". I was checking on her in real-time through the camera to see how she was responding to my call" (Frida, 76-80).

In this case, Frida utilised the AT to visualise the way her mother was responding to her voice. In other words, the monitoring camera became a mediator (that is, an extension of Frida's eyes) of the experience. She disclosed that her unconventional approach was used only during the nurse's shift. She appropriated the technology in this way since her mother's aggressive episodes had become difficult to control on previous occasions. Finally, Frida concluded her interview by sharing how the *technology changed her daily routine*.

"I wake up in the morning, pick up my mobile to see if there are any messages and then I check the cameras. Then at midday, I check if she has been sat down to eat or if any of my sisters are visiting her. So like I said, you check [the cameras/videos] to see that everything is fine, if she is asleep, and so forth..." (Frida, 432-436).

The AT became part of her daily life since it provided Frida with a new approach to her caregiving style. It also changed her behaviour and feelings, since she was able to manage her role in a much more convenient way. Overall, Frida's feelings were reported as positive towards the use of the technology since she found multiple beneficial uses that surpassed the initial intended purpose of the AT. Table 4.3.4.1 below summaries all the aforementioned superordinates and subordinates from this account.

Superordinates	Subordinates
Influence of her family	Healthy relationship with her family
	Implicit gender roles
Emotional reactions after diagnosis	Overprotective of her mother
	Defensive behaviour
	Patronised the nurse
Assimilate the diagnosis	Denial
	Anticipatory grief
Technology served as an assistant	Technology helped her preserve memories
	Technology was used to assist the nurse
	Technology changed her daily routine

Table 4.3.4.1. Summary of Frida's idiographic analysis

Table 4.3.4.2., is a small sample from the analysis of Frida's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.4.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Superordinate Themes
My brother decided that we were going to put them[cameras] in the house.	Brother decided to place cameras that he had previously known and used.	descriptive	13	Men as a decision maker	Machismo culture
The house was of two floors so we had them[cameras] in the area of the bedroom, in the staircase so that the staircase could be seen and the hallway upstairs.	Placed cameras in strategic areas around the house	descriptive	14-16	Cameras placed strategically	
She lived well, she could shower herself, she assisted herself for everything, but we had the cameras because she lived alone with a housemaid who has been with us for many years and is like part of the family. We worried my mum could fall from the stairs because it is a very long staircase and she would go down sometimes at midnight.	Used the cameras to prevent falls and to allow her mother to be independent.	descriptive	22-26	Technology provided independence	Technology as a care support
We[family] made her a room very similar to her own bedroom. We brought all of her furniture to the new room.	Family modified the mother's household to keep her safe with the familiarity of her belongings.	descriptive	31-32	House alterations for safety	Need for home alterations

Table 4.3.4.2. Sample Data Analysis from Frida

Reflective Box

I found Frida's interview very pleasant and engaging. Frida appeared to be comfortable with my presence. I assumed this from her welcoming personality and by the way she extended me her hospitality. For example, from the moment I arrived at her home, she offered me a drink, asked me if the room temperature was OK, and so forth. My first impression of her was positive, however, in the two hours we spent together, my perception of her changed. In the beginning, I saw her as a warm woman with a great sense of humour. She laughed many times during the interview. One of the things that made me feel comfortable during the interview was that she was able to articulate her emotions easily, making her answers very detailed. However, half-way through the interview I found it difficult to follow up her story because two things started to happen: 1) she deviated completely from the topic and I had to improvise questions that somehow would bring us back to the narrative; and on other occasions, 2) Frida's answers became so extensive that by the time she finished speaking she had forgotten what the main question was.

"...we have been very lucky, thank God... however... Oh God, I just forgot what your question was [laughs]" (Frida, 366-367).

I think that she felt confident enough to share details of her story because while she was narrating, I was reacting with empathic gestures. For instance, there was a moment when she was speaking about a vulnerable memory and her eyes grew teary. My first reaction was to say: "It's ok, take your time", since I wanted her to be comfortable and feel free to speak. Her reaction to my statement was emotional, with her beginning to cry. She felt safe but that changed the pace and ambience of the interview. After the emotional display, I had to briefly stop the interview and provide her with the water bottle and tissues I had brought with me. After that moment, the interview became very emotionally charged. With this, I mean that she went from being a happy, bubbly person to a vulnerable one that expressed the sadness that dementia brought to her life. With this in mind, I was able to then objectively divide into two sections the interview during the analysis process. The first half, up to the aforementioned tearful event, was very descriptive and the rest of the interview was emotionally rich. Furthermore, in her interview, I also noticed that she only mentioned her sisters when describing her mother's care. I found that odd because she also mentioned at the beginning of the interview that she had a brother. I believe that it was obvious during the interview that I was puzzled by this specific remark since I questioned her about her brother five times. I acknowledge that this affected the interview because to her it was irrelevant to speak about her brother. I assumed that if she wanted to open up about him, she would have done it. In retrospect, I think I was so inquisitive about her brother because I had personally experienced that unwritten rule of 'men do not get involved with caring duties' during my own

experience with my grandmother's care. I felt it was unfair and sexist.

When I analysed her case, I had to bracket a very specific opinion I formed about Frida. I categorised her as a wealthy woman. This formed opinion was based on the place that she lived, the quality of the technology she disclosed and the resources that were available to her during her experience (for example, having sufficient money to hire an architect). I inferred that the reason that I could not see past that in the beginning was because I believed she was in a privileged position. I saw her as a woman that did not have to worry about money and the public system since she had access to private doctors. Therefore, during the analysis, I had to constantly revisit my emotions to comprehend why I had this view about her. I soon realised that my issue with this was that I could no longer feel empathy when reading her passages since I judged her harshly. I felt that since she was in a privileged position, she was not entitled to speak, think, feel and act as she did during the interview. However, once I put myself in her shoes I realised that I would have certainly acted as she did.

Findings from Frida's account

The following are key findings in respect to Frida's account.

- The AT changed Frida's daily routine.
- The surveillance camera with recording features allowed Frida to preserve videos containing memories of her with her mother (i.e., person with dementia).
- Frida used the surveillance camera as an extension of her body (e.g. eyes) to assist the nurses, in real-time but from a distance.
- Frida experienced anticipatory grief.
- Frida indicated less caregiving burden. In her case, this occurred because she had a support network (e.g., family, nurses) that was willing to do their allocated roles.

4.3.5 Camila's account

Camila was a married woman with children and she was her mother's primary caregiver. Her mother was diagnosed with senile dementia at the age of 80. During her interview, she commented on how close she was with her parents throughout her life. They were so close that they built their homes together; she had lived next door to her mother since the day she was married. Their homes even had a connecting door for access when needed. She was closest to her father and she explained that when he passed away, it was the biggest loss of her life. Camila had an *estranged relationship with [her] brother* that resulted in many **family problems**. On various occasions throughout the interview, she spoke poorly of her brother.

"When she [mother] turned 80 years old we took her car away. Well... I did not, my brother did" (Camila, 205).

"...he [brother] is more apprehensive. So, my mum is my mum and my brother is my brother. And we had a lot of arguments over this because he wanted me to stay with my mother 24 hours a day but I have a house, a husband, children. So, I could not stay with her 24 hours a day" (Camila, 286-289).

"...she [mother] stayed like three weeks in the hospital because of my brother's foolish ways" (Camila, 249-250).

Camila's statements indicated an inherent tension with her brother. Based on the previous statements, Camila had a negative perception of her sibling. In the previous quotes, she openly described him as apprehensive, foolish and even blamed him. Furthermore, the root of this hostile relationship could be explained by Camila's belief that her mother treated her unequally to her brother. Although she praised her mother and even at some points exaggerated the love for her, she repeated throughout the interview that her sibling was her mother's favourite child.

"My mom cannot see anyone but her son. She cannot see you even though she has known you for twenty years, but the moment she sees her son, her world lights up. And you see it! You see it! Even with the dementia she has. It is like the world is new again. No, no, this ungrateful mother loves that son and this has been going on since the day he was born" (Camila, 385-388).

"They [parents] loved me and I was spoiled, but her [mother] favourite has always been him [brother]" (Camila, 390).

"And that's how it always was, always, always, and if I ever took my brother to my parents' house... my mother would leave everything she was doing to go and see her child [brother]" (Camila, 390-391).

"My brother tells me off, but since he is the favourite one..." (Camila, 701).

These statements reflected an implicit jealousy towards her brother. Based on her sarcastic tone, eye contact and overall analysis of the interview, she appeared to hold a grudge against her sibling and a *hidden resentment towards her mother*. Camila felt like the nonpreferred child all her life. It appeared that her mother had been very transparent about her favouritism, making Camila resent her. This supposition explained her closeness to her father and antagonism towards her brother. Furthermore, Camila expressed how **assimilating the diagnosis of dementia** was very challenging to her. The following example illustrates Camila's journey into *making sense of the diagnosis*.

"There are so many people right now with senile dementia and Alzheimer's disease that you ask yourself why? Something must be happening" (Camila, 688-689).

"I do not know, I do not know if it is because she had a job, she was very active, very positive, very... and what was the trigger for dementia? I would like to know what happened. Why do things happen? There must be a reason" (Camila, 693-696).

These passages demonstrate the way Camila assimilating the diagnosis. At that moment, she had not accepted that her mother had dementia. It appeared that her priority was her 'need to know' what caused her to develop dementia. Camila's inherent 'need to know' suggested that she was determined to find her mother the best medical care. However, since it is impossible to know what exactly triggers dementia, assimilating her mother's illness was challenging to her. Additionally, Camila explained how she knew that she had to assume the caregiving role after learning about her mother's diagnosis.

"So... taking care of my mum? ... I already knew. I already knew that I was going to take care of her, sooner rather than later" (Camila, 382-383).

"I already knew that I was going to take care of her. I am the only daughter; I do not have another choice. So I will do it by myself" (Camila, 399-400).

Accepting her caregiving role was a daunting task for her. She loved her mother, but she never wanted to be her caregiver. Camila's extracts exhibited how she was already anticipating the caregiver role. Camila repeating the phrase "*I already knew*" suggested that she unwillingly assumed the role of caregiver since her brother appeared to dislike playing the role of carer. This assumption was based on the quote below where Camila explained how during one of her holidays, she asked her brother to take over their mother's care.

"She [mother] used to eat alone, but my brother hired a girl [nurse] to take care of her [during Camila's holiday] and she started feeding her directly into her mouth. To this day, my mum no longer knows what a fork is used for" (Camila, 254-255).

Her brother's actions suggested he was not keen about caring duties and instead decided to hire a nurse for the duration of her sister's holiday. Furthermore, Camila's story also hinted at the embedded value of familism since she displayed loyalty and a sense of duty towards her parents. She expressed:

"I was always with my parents. We [husband and Camila] travelled with my parents, we went to eat with my parents" (Camila, 380-381).

"I looked at it [caregiving] like it was my duty to take care of my mother" (Camila, 327).

This cultural value had an impact on her decision to provide for her mother's needs. She assumed the role since she saw it as a 'duty'. Camila treated her role as a regular 'paid job', like having a 9-5 shift with rules, expectations and a 'symbolic' line manager (namely, her brother). Following this approach, Camila was able to set aside her feelings and assume the role. Familism, in this context, was interpreted as obligatory support. Consequently, she then described the unfolding *disadvantages of her caregiving role*. For example, she stated:

"I finish so tired that I do not even want to do it [care for mother] the next day. I do not know if it has been more or less tiring now that my mom is here [at her home]" (Camila, 454-456).

"From my family, the only one that helps financially is me" (Camila, 529-530).

The previous passages described two ways in which Camila's experienced caregiving burden. The first quote explained her experience of physical burden. This concept was explored in section 2.3.3, namely, exposing the body to highly demanding activities that could result in malnourishment, dehydration, or exhaustion, and limiting the body's capabilities. Camila was experiencing exhaustion since she dedicated all her time to her mother's care, neglecting herself. Furthermore, Camila described in the second quotation how she was the sole source of financial support for her mother. This burdensome feeling is referred to as a financial burden. The concept was introduced in section 2.3.3, namely, monetary expenses and work-related adjustments that a caregiver has to endure as a way to provide for the care needs of the affected family member. Since Camila's brother did not make any contribution, she faced the financial burden alone that consequently limited the amount of help she could get from other places. She could not afford to hire a nurse, so she opted to place a monitoring camera in her mother's bedroom to observe her when she was away from her mother. Even though the camera decreased the number of visits to her mother's bedroom, Camila still felt burdened. She described how she experienced depression, isolation, and other **psychological effects** as a consequence of her caregiving role.

"I felt my life was falling apart because I was not there for them [her husband and children]" (Camila, 306-307).

"It saddens me to see her like that because my mum was very active. So, it makes you sad to see her there, sitting down, watching TV and you cannot take her anywhere" (Camila, 416-417).

These statements described the *emotional pain* Camila experienced being her mother's caregiver. Despair, sadness and frustration are some of the emotions that she felt on a daily basis. Camila felt overwhelmed by her role since she thought she was missing out in life. In the first quotation, her expression "*my life was falling apart*" was interpreted as Camila's guilt since she believed she was neglecting her husband and children. The second extract embodied the painful feeling of impotence. Camila felt this way because she knew that dementia had overcome her mother. She was accepting the reality that her mother's essence was slowly fading away from her body. Hence, the combination of all these contributors affected Camila's mental health. Camila expressed how *constrained* she felt with her role.

"I do not have time to go to the salon, I do not have time to get a manicure, pedicure. Shopping centres? I know nothing, they have places open that I do not know about. The other day they told me about a place called [name of shopping centre]. What is that? Please understand that I have had a year and a half or more that I have not left my house" (Camila, 443-446).

"Honestly, there are days when I do believe it [dementia] ruined my life" (Camila, 528).

"It does ruin your life because I cannot do anything, not even go out" (Camila, 533).

"Well, you have no choice, because there is no one who will help you. There is no one ... will there ever be a solution? No, there is not, things will remain the same" (Camila, 542-543).

These quotations projected the anger Camila felt as a result of her isolated and constrained life. She resented that she had to push herself away from her social circle to comply with her mother's care since her brother did not help her. This left her feeling like a misfit and she craved her old life. To Camila, dementia was a thief. The second and third statement supported this interpretation. In a metaphorical way, dementia robbed Camila's mother's health, financial stability, personal time, and social life in an unexpected way. Camila believed that dementia "ruined" her life because, in hindsight, it affected all her family and friends. Families are affected since they know that a person with dementia will eventually forget them and bring major life changes to all of them. To a certain extent, friends are affected too because the caregiver will stop nurturing those relationships. Nonetheless, this was not enough and as an *escape mechanism*, she would bet once a week on fruit machines in casinos.

"I go once a week and those two hours or three hours I go are for me. It makes me forget about my mum because I really need that alone time" (Camila, 432-434).

"Let me tell you, in the day I cannot go out. At night, what is open? Well, the fruit machines. I'm not going to a bar because I do not drink, I do not go to restaurants because they close early. I finish with my mum at 11pm because there is no one that can care for her before. Then I go to the fruit machines, I sit down, I talk to my friends and they [casino employees] take care of me and I entertain myself" (Camila, 434-437).

The Merriam-Webster dictionary (Merriam-Webster.com, 2019) defines an escape mechanism as "a mode of behaviour or thinking adopted to evade unpleasant facts or responsibilities". Camila's statements supported this concept since caregiving was a burdensome experience. Camila wanted to break away from her responsibilities. She found comfort in gambling once a week, as long as her duties permitted. Camila appeared to enjoy the gambling experience because it offered a social environment for her. This was implied from the emphasis she put on the friends she made since she became a regular at the casino. Camila's escape mechanism could also be interpreted as a way for her to feel relief from her daily stressors. It appeared that these types of environments were an ideal place for her to relax since they gave her the opportunity to socialise, have fun, and be served food. Camila's story was very rich and detailed, giving an extraordinary new look into a caregiver lived experience with **technology as a positive influence**. For instance, she explained the different ways in which the *technology improved her life*.

"I usually had to shower late at night until she [mother] was asleep. Sometimes, I had to shower at midnight. But with this little camera, all my problems are solved" (Camila, 155-157).

"...100% because it takes away your worry of being up and down the stairs. And you get really tired. I am in my fifties; it is not easy to do these things [laughs]. This little camera has worked wonderfully for me" (Camila, 664-666).

"...I can monitor my mother all the time – 24 hours a day – and not be next to her 24 hours a day. It gives me peace of mind because even though I'm in my bed, I can see her from there" (Camila, 622-624).

Since getting the surveillance camera, Camila experienced positive changes in her life. All these statements conveyed that the AT provided Camila with a sense of freedom and a space for flexibility within her role. For example, she described how she was able to shower whenever she wanted, her trips to her mother's bedroom were reduced, and she could monitor her from any place with an internet connection. In the first and second quotations, Camila mentioned "*this little camera*", followed by a positive comment about the AT. In the third one, she expressed "*gives me peace of mind*". These statements suggested the AT was benefiting her life in a practical, financial, and legal way. The AT allowed her the accessibility to monitor her mother conveniently. She was able to practically monitor

her mother with her mobile phone just using a WiFi connection. The AT was also able to prevent any nurses from being hired and making unnecessary commutes, reducing her expenses. Finally, the AT made her feel that she was providing dignified care to her mother (and therefore complying with Mexican law) because she felt that with the AT she was providing better care. Camila also explained how the technology gave her a sense of *ubiquity*.

"I go somewhere and I am [watching] with the little camera" (Camila, 8-9).

"I have it connected to my mobile phone... it needs an internet connection because you can see it [monitoring camera] anywhere in the world" (Camila, 32, 36-37).

"Yes, let me show you how it works. Let's check if my mother is awake. Look at this [hands over phone to interviewer]" (Camila, 119).

To Camila, the AT gave her a solution to what she perceived as a problem, namely her caring role. She wanted her old lifestyle back but she still wanted to serve her mother. This ambivalent feeling was decreased with the newfound state of ubiquity. She was able to create a schedule and plan around the AT, giving her a sense of control over her role. Thus, if she planned well, she could go out and enjoy time with friends without losing sight of her mother. This functionality empowered Camila and helped her decrease her perceived burden. Finally, Camila disclosed that she had been complying with this imposed role for five years up until the time of the interview.

Table 4.3.5.1 below, presents the summary of Camila's account.

Superordinates	Subordinates
Family problems	Estranged relationship with brother
	Hidden resentment towards her mother
Assimilating the diagnosis of dementia	Making sense of the diagnosis
	Accepting her caregiving role
	Disadvantages of her caregiving role
Psychological effects	Emotional pain
	Constrained
	Escape mechanism
Technology as a positive influence	Technology improved her life
	Ubiquity

Table 4.3.5.1. Summary of Camila's idiographic analysis

Table 4.3.5.2., is a small sample from the analysis of Camila's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.5.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 15-Camila Time: 1:10 Total lines of transcript: 771					
Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Superordinate Themes
I use the monitoring cameras to be always watching. My mom is in bed, so I don't need to be with her all the time because she does not stand up. So I'm there seeing her as .. If she woke up, if she did not wake up, if she moved or if she did not move, if she wants something or does not want something, if she changes the TV channel. I see everything in the little camera.	The reasons why she uses the camera. Monitoring her mother	descriptive	4-7	Technology for monitoring purposes	Technological needs
I go somewhere and I am [watching] with the little camera.	Obsession?Addiction? With technology. Constant need to observe her mother. Big dependence.	descriptive	8-9	Dependence to the technology	
It is in colour. It moves, you can move it, you can turn it, you can talk to it. It has a microphone...I hear what my mom is hearing or saying.	Functionalities from the technology. She understands what the technology does.	descriptive	14,18,22,27	Technology functionality	
I have it connected to my mobile phone...it needs an internet connection because you can see it anywhere in the world with it.	Convenience of use. A practical and mobile technology.	descriptive	32,36-37	Thinks it is a practical technology	Acceptance of technology

Table 4.3.5.2. Sample Data Analysis from Camila

Reflective Box

Camila's interview was the only one that did not take place in the participant's home. She asked me to meet at the Alzheimer's Association offices and also asked me to be very punctual. She was the first person who had asked me for such specific things before her interview. Therefore, I formed a somewhat negative first impression of her. The image I had of her was that of a person hungry for control. When I was finally able to start the interview, I realised that my idea of her was beginning to change. This image now evolved into one where I saw Camila as a funny and smiling lady. I created this image based on the constant pauses we had to have because she couldn't stop laughing. Camila was quite open with me about her experience and was also the only participant that allowed me to see in the first encounter how her technology worked. That is, she allowed me to see real-time transmission of her mother with her mobile phone. This moment was important for me since I could see how she interacted with the screen of her mobile phone and how she was reacting to what she saw. In other words, I was able to witness her emotions, first-hand, during her interaction with the technology. After this moment, I was able to understand why she asked me to be punctual and to have the interview somewhere else. She explained to me that she was grateful I was punctual because once the interview finished she had to run back to her house to feed her mother. She also explained that she needed the interview somewhere different to her house since she spends all day there and wanted to get out. I felt that this truthful interaction and disclosure affected the results of her analysis in a positive way. During her analysis, I returned to those valuable moments that I was able to witness first-hand. There was a moment during the interview that I noticed a pattern of contradiction. For example:

"I cannot do anything now. Before it was us [husband and her] against the world and now this world spins around my mother" (Camila, 485-486).

"My mum gave me everything. She gave me her entire life. She was my best friend." (Camila, 406).

In these passages, it was evident that she was firstly complaining about her mother and later referred to her as her best friend. The persistence of these continuous contrasts made her analysis complex. For example, I had to divide all the positive and negative references she expressed about people, things, or situations. Then, I had to count the number of incidents of these references and in the end, I had to consider which ones really matched the narrative. I recognised that due to the contrasting nature of this case, the final result could be perceived and interpreted differently by someone else.

Findings from Camila's account

The following key findings summarises Camila's account

- Camila described high levels of caregiver burden because she lacked a support system network (e.g., family).
- Camila's provision of care to her mother was affected by the poor relationship she had with her mother.
- Camila adopted an AT after she accepted that her mother was affected with dementia.
- The AT provided Camila with a sense of ubiquity.

4.3.6 Pablo's account

Pablo is a shy, quiet and serious man that responded with curt answers. His father was diagnosed with vascular dementia four years before the interview. Pablo has one sibling, who is younger than him. He decided to move in with his father voluntarily right after his mother passed away many years ago. He told the researcher that before his father's diagnosis, they had a close father-son relationship. Pablo emphasised how everything changed after his father started showing the characteristic symptoms of dementia. The strong foundation of Pablo's **instilled values** drove him to voluntarily assume the role of his father's primary caregiver as he felt it was his *duty as a son*. Pablo explained his choice by expressing:

"One reason is because I am not married. So I am the one who has always been with dad. I live here in his house. My brother is married and I, I, I was the one who said to him: "You have way more responsibilities than me." He has a family. This role does not take anything away from me. I chose this rather than going to parties or meetings. That's how I am... that's me... It was the decision I made. Nobody forced me to be dad's carer. It was my decision. Nobody decided that. I assumed the role because he is my dad. That is the main reason" (Pablo, 229-235).

Pablo's sense of moral obligation to support his father during this difficult time was the force that drove him to become his caregiver. The first quote shows how Pablo was diligently trying to self-justify his caregiving role. He was defending his choice and making it clear that it was voluntary. In the second sentence, Pablo stumbled with a stutter "*I, I, I was...*". This speech impediment was interpreted as Pablo trying to self-validate his caregiving role. When he tried to do this, his accumulated anxiety led him to respond with a stutter. Pablo's statement contained a personal and emotional reaction to a private matter (namely, his father's dementia diagnosis). It appeared he was uncomfortable explaining why he assumed the role since for him, caring for one's parents is normal in his culture. Furthermore, Pablo also described how he has a *close relationship with his family*. For instance, he expressed:

"Well, the one who is almost 100% is really me because I wanted it that way. My brother comes and visits him, he's here. He usually says to me: 'You have to leave, go out and I'll stay here with dad'. You know? We take turns" (Pablo, 127-129).

"Also, my nephews come and help us [brother and Pablo] with dad" (Pablo, 196-197).

These statements suggest that Pablo felt supported by his family and trusts them. It could also be implied that his brother sincerely cared about him because he made Pablo take breaks for his mental health. Notwithstanding, an interesting element of Pablo's story is that he only spoke about the men and not about the women of his family during his interview. The other females that he

referred to are the nurses that he occasionally hired to care for his father. Some details from Pablo's life might explain this unusual circumstance. Pablo's mother was the only woman in his nuclear family and passed away many years ago. His brother, who is married, only had sons with his wife, which Pablo did not speak about. Pablo also stated that he had never married and did not disclose any romantic relationship. After taking all these elements into consideration, it can be concluded that Pablo did not have any 'direct' female family members that could be part of his support network. Therefore, Pablo's circumstances indirectly gave him a substantial reason to adopt his role. In addition, Pablo expressed how all the rapid changes in his life made him feel scared and **uneducated about dementia**. Pablo explained how he *learned about the disease by experience*.

"It could be, but not all patients are the same. It is very difficult, maybe they could tell us: "if he gets upset, talk nicely or talk about his past". There are no real recommendations, that's up to oneself. It is the experience that you have had with him over the years that really helps" (Pablo, 202-205).

"Yes. Sometimes we make mistakes, but as the saying goes, "you learn from your mistakes". I am telling you – I hope I don't sound dramatic but that's the way it is. Just like in every aspect of life. You always make mistakes and you must learn from your mistakes so that you may grow as an individual" (Pablo, 287-290).

To Pablo, experience was more valuable than any advice he could be offered. Pablo was slowly learning from the mistakes he made with his own father to provide adequate care. This trial and error approach suggested that Pablo believed that tacit knowledge extracted from the one-to-one interactions between the carer and the person with dementia is superior and more informative than other methods. In the same vein, Pablo described that he felt that there is a *lack of information about dementia* in Mexico. He expressed:

"There is a lack of information on how you can monitor a person with dementia and how to help them." (Pablo, 46).

This statement suggested that he wanted to learn more but felt there is not enough awareness of the condition. Pablo had to reduce participation in his social life, hobbies and even reduce his working hours to provide care for his father. Taking this into consideration, Pablo perceived this paucity of information because he had less time to research information (for example, multiple responsibilities) and less time to learn from friends or family (such as word of mouth). As a consequence of all the changes in his life, he started to develop symptoms of **caregiver burden**.

"Oh yeah! A lot. He who does not feel stress does not know what it is to have a person with dementia" (Pablo, 253).

Pablo described *stress* as a frequent incidence in his life as a caregiver. His poetic use of words implied that feeling stress is a must during the experience. He also suggested that if a caregiver does not experience stress, it must be because they are not doing enough as a carer. It was also difficult for Pablo to approach subjects with emotionally charged content. However, through an in-depth interview, Pablo was able to open up and provide a narrative in which the researcher had the space to interpret his enclosed and/or abstract feelings. He also expressed how difficult it was to deal with his *father's night wanderings*.

"The nights. The nights are difficult because he doesn't sleep continuously. He gets up to go to the toilet, he feels disoriented and says over and over again "I want to go to my house"" (Pablo, 256-257).

It can be implied with the last statement that, to Pablo, the most challenging part of being a caregiver was controlling his father's aimless movements at night. During Pablo's interview, he described how difficult and expensive it was to get medical attention for someone with dementia. Hence, getting a prescription for his father's wandering would have been a laborious task. Pablo and his brother financed all of their father's needs (for example, medicines, diapers, paying bills, and so forth). Notwithstanding this, Pablo disclosed that even with his brother's support, paying for a private consultation to get medicines was out of their price range. Pablo showed great resilience and **emotional self-regulation**, in spite of the difficulties he talked about.

"Well, sometimes it works, sometimes it does not. I do not get frustrated, I think, I breathe, I talk on the phone [with brother], I ask him 'what should I do?' I withdraw; I hide in my little world. If not, I consider other options; I talk to my brother: 'hey dad is like this, he does not want to understand, what do I do?' And he says: 'put him on the phone'. And when my dad hears a different voice, he calms down" (Pablo, 207-210).

Pablo's statement demonstrated his individualistic and rational side. He is a man who used a *task-oriented approach* instead of an emotional-oriented one. His expressions "*I think, I breathe... I withdraw; I hide in my little word*" appeared to be a methodical procedure that he adhered to when his emotions were trying to cloud his judgement. Pablo's caregiving style could be interpreted as oriented towards problem-solving. He attempted to *rationalise events* and circumstances to understand the world around him.

"But there is not one single solution... if he reacts in this way or if he becomes restless... do this... There is no rule, solution, do this, do the other. Nothing! Everything is just a matter of one's personality, of observing what the person is going to do next. Sometimes there is a solution a) – that works, then you re-apply solution a). But it does not work. Then you try b), then c), you start to make up solutions, we even try to imagine what dad could want. And we try to see if it works" (Pablo, 184-188).

When Pablo was able to solve a problem, rationally, he remained calm. However, when a situation was unpredictable or out of his control, he felt frustrated. This interpretation was based on the explanation he gave for his continuous attempts to control his father's behaviours. He was focused on solving the problem and in an organised manner, he reviewed followed steps to assess his father himself. Therefore, not finding a way or solution after his methodical review made him feel frustrated. Pablo also disclosed he had a flexible working schedule since he was self-employed. As his schedule was unpredictable, he hired nurses who helped whenever he needed to go out for a job. A key point of our interview was that one day after Pablo arrived from work, he noticed bruises on his father's arms. He called his sibling and they decided to place a hidden surveillance camera to watch his father's movements. Initially, they suspected that his father was falling from the bed or toilet. That camera allowed him to monitor his father when he was working on his mobile phone. He was very vocal about the benefits and his own personal opinions about the assistive technology. Pablo perceived the **technology as an enabler of care** because it allowed him to provide better care to his father. He said:

"...when there is no one to take care of dad. That's when the camera is used. To see if dad needs something" (Pablo, 17-18).

He suggested with this statement that the AT was being used as a *temporary substitute* for in-home caregiving. This was interpreted as if Pablo was using the AT to detach from his role as caregiver. It appeared that Pablo adopted this technology for its utility since it helped him solve a specific issue; namely, leaving his father unsupervised. To Pablo, this was a practical and neutral solution because it removed the responsibility of having to be physically present. From his perspective, Pablo believed the AT acted as a substitute for his caregiving role since he could monitor his father at any time. Furthermore, Pablo described how with the help of the surveillance camera they discovered an abuse situation and fired the nurse responsible.

"I suggested we should watch the recorded videos from the camera to see the nurses work and we discovered abuse. We fired the nurse responsible, but we did not tell her the reason. We just told her 'we no longer need your services' and that was it" (Pablo, 222-224).

It was previously mentioned that Pablo found suspicious bruises on his father's arms. The hidden surveillance camera *helped him identify elderly abuse*. The previous extract described the moment when Pablo learned that the nurses were abusing his father. He was shocked because he never suspected any malice from any nurse. This moment made Pablo appropriate technology in a new way; namely to monitor the nurses. At first, he just needed the camera to monitor his father's behaviours, then he realised that the AT had the potential to act as a substitute for his caregiving role. Since he realised his role could not be supplanted by the AT, his circumstances made him refocus his use to the monitoring of nurses. Ever since the incident, Pablo decided to just work part-time in order to take better care of his dad. The incident affected his ability to trust others and, as a consequence, he decided to permanently use the camera as part of his caregiving routine. The table 4.3.6.1 below summarises Pablo's account.

Superordinates	Subordinates
Instilled values	Duty as a son
	Close relationship with his family
Uneducated about dementia	Learned about the disease by experience
	Lack of information about dementia
Caregiver burden	Stress
	Father's night wanderings
Emotional self-regulation	Task-oriented approach
	Rationalise events
Technology as an enabler of care	Temporary substitute
	Helped him identify elderly abuse

Table 4.3.6.1 Summary of Pablo's idiographic analysis

Table 4.3.6.2., is a small sample from the analysis of Pablo's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.6.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 21-Pablo Time: 00:31:52 Total lines of transcript: 304					
Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Super-ordinate Themes
Nobody, just between my brother and I. We decided this. We thought about how can we check up on dad and the solution we thought was to get a camera.	Takes important decisions with brother. They have a good relationship and he acknowledges his opinions.	descriptive	14-15	Takes important decisions with brother.	Confides in brother
...when there is no one to take care of dad. That's when the camera is used. To see dad if needs something.	Camera is used to monitor the father when Pablo or his brother are not available. Almost like the camera was a temporary carer.	descriptive	17-18	Technology as temporary substitute for carer.	Technology as an enabler of care
No, we did not think about it[privacy issues]. What mattered was his well being, we wanted to take good care of him.	Never thought of privacy issues. He truly believes this was the right solution for his problem.	descriptive	34	Trusts the technology	Opinions about technology
No, not that I know of. It's not a ... as I'd said ... I think there's a lack of information.	He sees value in the camera he bought, but he can't describe it. Like if he doesn't know all the functionalities of the camera. To the present time, he cannot recall a moment where the camera helped him prevent an accident.	descriptive	43-44	Unaware of all the technology's features.	
...information for family members who have this type of person	"This type of people" sounds like he sees people with dementia as	linguistic	44	Labels people who	Epistemic Normativity

Table 4.3.6.2. Sample Data Analysis from Pablo

Reflective Box

Booking an interview with Pablo was difficult because he did not have fixed working hours and we had to work every day of the week. Pablo was the only male that allowed me to interview him. I saw this as a unique opportunity and I prepared for this interview differently to the others. To start with, all the phone interactions I had with Pablo whilst trying to establish a day and hour for our interview were very short. I had noticed that his utterances were brief, therefore I prepared myself with extra follow-up questions. The day of his interview, I felt well prepared and I was eagerly counting the hours until his interview. To my disbelief, he texted me early in the day to change the hour due to unforeseen circumstances. This worried me because I was afraid he might cancel. I had now formed the impression that Pablo was trying to avoid the interview. Thankfully, this was not the case and the interview did happen at the newly established time. When he greeted me at his door, the experience was completely different to the experience with the female participants. Pablo did not show hospitality or try to make small talk. I could feel tension between us and I was utterly uncomfortable. The interview was carried out in his living room and he left the TV on during the interview. Before we started, I asked him if we could turn the TV off to which he responded, "No, because if I do my father will wake up and the interview will be interrupted". This was a new challenge for me. I started the interview by making sure that the recording device was very close to Pablo to capture his voice. I believe that having the TV on affected our interview significantly because I noticed that Pablo was easily distracted by the light it emitted. I was also restricted because I had to raise my voice to override the sound of the TV, but I was cautious to avoid waking up his father. As the interview progressed, I could see Pablo was trying to deflect any question that would require emotions. I decided to speak more than in the other interviews and find relatable experiences that would make Pablo open to me. All questions related to the technology were answered briefly and with a neutral tone. For example:

Researcher: "Can you please describe to me, in detail, what was the technology that you are using to care for your father?"

Pablo: "It is a surveillance camera"

Researcher: "What are some of the main functionalities of the camera?"

Pablo: "It has audio". (1-4).

In contrast, the moment Pablo started to open up to me was when I asked him about his father's diagnosis and the story behind it. He expressed himself as follows:

Researcher: Can you please tell me the story of your father's diagnosis?"

Pablo: "Oh yes! Well, dad has been like this for around... four years. He started having problems when walking. My dad is not completely healthy; he also has heart problems..." (179-182).

I have three theories for his contrasting reactions: 1) at the beginning of the interview, he did not feel comfortable enough to open up since I was just a stranger; 2) the questions that required the expression of his feelings were prompted mid-way through the interview; and 3) he really wanted to speak about his feelings since there were no female figures in his life (that he disclosed). Whichever is true, I am thankful that, to the best of his ability, he did open up about his experience. After hearing him sharing his feelings, I was able to change my impression of him. Now, I saw a hardworking man that was trying to provide the best care that he could for his father. I understood that he never expected this situation to happen to him because he was not brought up to be a carer. I also learned that all my previous interviews and interactions with female caregivers gave me a certain impression of the nature of carers. I was wrong, there is not a universal formula because there are not only biological differences (for example, how our brains work); there are also values (for example, machismo, familism, feminism, and so forth) that, from childhood, forge who a person is and have a tremendous impact on how they react in the world as adults.

Findings from Pablo's account

The following are the key findings from Pablo's analysis.

- Pablo learned about dementia through his experiences and observation.
- Pablo used the ATs for surveillance of his father and the nurses that interacted with him.
- The ATs allowed Pablo to balance his work hours.

4.3.7 Valentina's account

Valentina came from a family with many siblings. Her story was one of struggle and pain as her family was one with scarce resources and she had no support from her siblings. Her mother lived with Alzheimer's disease for 15 years before her passing. Valentina was forced into the role of her mother's primary caregiver as a result of the **influence of cultural values** in her family. Her siblings firmly believed that, because she was single and lived at her parents' house at the time of diagnosis, she had to assume the role of caregiver. Valentina's mother was a widow which explains why her husband was not a candidate to assume the caregiving role. In the first years following the diagnosis, Valentina felt that her role as primary caregiver was assigned in a discriminatory manner since it was based on the premise that a single woman is the best candidate for the caring role. Valentina's sisters helped from time to time with some caregiving activities, but her brothers did not. Despite the *unfair distribution of roles*, she only expressed resentment towards her sisters and not her brothers.

"My sisters. That was the most shocking thing because my brothers, they were only [financial] providers. They did not participate in the proper care of mum. So, they just paid for things... things that she needed" (Valentina, 193-196).

Valentina expressed how she felt 'shocked' that her sisters did not make a greater effort to care for their mother. As an example, Valentina explained that she often would look to her sisters "*...but nobody supported me*" (Valentina, 257). She wanted them to help her more because she never wanted to become the primary caregiver in the first place. Within this context, shocked is interpreted as emotional distress given that towards her sisters, Valentina became irritable and frustrated at the slightest things. As time went by, Valentina began to suspect that one of her sisters was not taking proper care of their mother since she was dehydrated and dirty after the sister's shifts. Therefore, she bought a surveillance camera and a baby monitor to hide in her mother's bedroom. Valentina began to monitor her sisters covertly since she knew that they would have never approved this decision. Valentina found recordings showing two of her sisters, in several instances, engaging in verbal abuse.

"We have recordings where some of my sisters were... well two of them, saying to my mum 'Hey mum, when are you dying? You've lasted quite a while!'" (Valentina, 214-216).

After this moment, Valentina lost all the little confidence she had in her sisters and decided to continue recording secretly as a precaution. Shortly after, Valentina got married and had a daughter. Her husband and daughter also lived in the same house as her mother so Valentina could continue her caregiver work. She recounted how having a daughter now made her perceive her caregiving role in a different way. She explained the *sense of fulfilment* she felt with her role.

"I felt like I was fulfilling my duty. Because if I'm honest, my mother mistreated me a lot because of my strong personality. I felt that I was somehow apologising to her for the way I had behaved with her in the past. I was very loud, I was very rebellious but very responsible with her care" (Valentina, 534-535, 538-540).

For Valentina, being her mother's caregiver became a moral duty. Having a daughter sensitised Valentina's way of thinking. Now her role as a caregiver had a new meaning that changed her attitude. In her statement, she explained how caring for her mother symbolised the apology she could never give for her rebellious years when she was younger. It could be interpreted that this symbolic apology is the way Valentina redeemed herself. Valentina also described how the multiple **changes after the diagnosis of dementia** changed her life forever. She explained how she had to schedule the time she spent with her daughter.

"I tried to make her [daughter] social life at night. My sister took care of my daughter in the morning, and I arranged her social life at night. I organised my daughter's world based on the time I could spend with her" (Valentina, 666-669).

To balance her life, Valentina began to be very organised with her time as her life priorities changed when she became a mother and caregiver. For instance, she had to reduce her working hours to part-time and her social life suffered equally. From time to time, two of her siblings would cover for her when she went to work because her family did not hire nurses. Valentina understood the great responsibility of being the caregiver of her mother, but the great number of responsibilities overwhelmed her. This desire to find a balance and the *double-care responsibilities* (that is, caring for both children and parents) overpowered her. Her expression "*I organise my daughter's world*" means all the activities and interactions that she, with difficulty, manipulated so that her daughter could have a life outside her grandmother's illness. This was because the disease absorbed the time Valentina could have with her daughter and limited the times that the girl could enjoy her social life with children her age. She also explained the different habits that she and her sisters adopted as a result of the diagnosis.

"So then, we [single sister and her] started taking folic acid, we changed our dental amalgams, we started to practice crafts. Everything that implies coordination and all that, knitting and embroidering all that. And my [other] sisters started to do imitate us and started doing word searches and reading books" (Valentina, 391-394).

Valentina decided to make drastic changes in her lifestyle since she did not want to end up like her mother. These *abrupt changes in her habits* were interpreted as the inherent fear Valentina had towards developing dementia in the future. She knew that some risk factors were modifiable (for example, diet and exercise) and some others were not (such as genetics). Therefore, the life changes made by Valentina made sense based on the high risk factor of genetics. Although some of her family members made changes to their habits, none of her siblings showed any interest in the care of their mother. Consequently, Valentina explained how she eventually managed to get all her siblings to help with their mother's care.

"And I have told you all [siblings] beforehand that you are going to care for mum, because it is also your obligation. And whoever does not comply, I'm going to sue you [for negligence] because you are not doing your job as her children" (Valentina, 464-466).

The previous quote exposed an aggressive side and *manipulative behaviour* from Valentina. She made the decision to threaten her siblings with legal action since she did not feel supported by them. Valentina alleged negligence from her siblings since her brothers stopped contributing with money and her sisters stopped helping with the care of their mother. In Mexico, neglecting an older adult is a crime. Valentina disclosed that she had recorded some of her sisters mistreating their mother and had bank statements to prove the lack of financial support from her brothers. This was enough proof to accuse them of negligence. Valentina wanted to sue them for two reasons: 1) to force her family to contribute either financially or with caring responsibilities (for example, caring shifts, preparing meals, cleaning, and so forth); and 2) to specifically prevent three of her siblings from sending their mother to a nursing home. Her siblings disclosed that they had intentions of sending their mother to a nursing home so that they could sell her assets (for example, her house, cars, and so on). It appeared that these specific siblings were struggling financially and thought they could take advantage of their mother's deteriorating state. Valentina knew that if she threatened her siblings with legal action, they would comply with her demands and stop their ill-intentioned actions. Valentina was a social worker who specialised in older adult care. Therefore, her siblings believed her threat. Valentina shared how she felt **misinformed about dementia** because at the time (the late 1990s) in Mexico the internet was just starting and there was a *lack of information* about Alzheimer's disease and related dementias. She explained:

"I looked for the information by myself and that is how I learnt about the existence of the Alzheimer's Association" (Valentina, 348).

"Technology was starting with the so-called 'internet'. They [medical doctors] told us to 'browse online'" (Valentina, 364).

"I went to every event they [Alzheimer's Association] did and they only talked about prevention. A lot of 'eat a lot of greens, eat a lot of reds, don't eat sausages, eat a measured diet'. But they didn't talk about what could help the patient" (Valentina, 405-408).

Valentina was clearly frustrated because she felt limited in her learning journey. Her expression *"I looked for the information by myself"* suggested that she was trying to be proactive at her role. She was trying to seek advice from the Alzheimer's disease Association (*"they didn't talk about what could help the patient"*) and information from medical doctors (*"they told us to 'browse online'"*). Notwithstanding, she realised that even though these people could be perceived as a reliable source for information, they were also experiencing the same learning curve as her. Her *willingness to learn* was soon being overshadowed by this overwhelming truth. The multiple speculations and guesses around the understanding of dementia, made her develop anxiety and depression, which she had for years. With her limited resources and vast capacity for creativity, she decided to **appropriate technology pragmatically** to monitor her mother's progression and spy on the siblings who also cared for her mother. She explained that she used the AT to engage in covert surveillance of her siblings, as they would constantly lie and mistreat their mother.

"The reason why we [husband and her] placed the cameras was for my mum's safety since she was looked after by multiple people. Not with malice because we didn't trust the people, but because there were some with little tolerance towards my mother. There were some legal circumstances that we knew that it would help me if in the future the people who were involved in the inheritance of my mother would sue me alleging I mistreated her" (Valentina, 27-29, 33-38).

In the previous statement, Valentina highlighted what could be perceived as contrasting arguments. Firstly, she stated that the surveillance camera was placed for safety purposes, namely, to protect her mother. After all, she had enough reasons to distrust and suspect her siblings since they had shown little interest for their mother in the past. She then explained that the recordings made with the surveillance camera were being saved as evidence, in case any of

her siblings filed a lawsuit against her for elderly abuse. These were two different uses. One could interpret this as self-interestedness since it appeared that she was only trying to protect herself and was trying to find reasons to accuse her siblings. The technology was not used for her mother's safety since she disclosed that her mother was bedridden during this period of time, "*my mother was bedridden*" (Valentina, 92). However, her life changed when she realised that the AT could be used in multiple ways. She explained:

"When I took her to her medical appointments, we first took her down in a chair and then in the wheelchair. And then she didn't want to walk anymore. So we took videos and took them to the doctor. This is how we received the medicines. With the evidence of video and photographs" (Valentina, 117-121).

In this case, the *AT was used for medical appointments*. Valentina came up with the pragmatic idea of bringing video recordings and photographs of her mother as supporting evidence to request her recurrent prescriptions. Since her mother was no longer able to attend her medical appointments, this approach made sense. During the interview, Valentina described this newfound use with excitement because it reduced the burden on her given that her mother's medicines were crucial to her wellbeing. This pragmatic use of the AT inspired Valentina to appropriate the camera in yet another way. She described how the *AT was used to store mementoes*.

"...images of my mum still being my mum. When she talked with my siblings, with me, with her grandchildren. Watching television because she really liked it. The most positive thing was that they [recordings] were left for posterity" (Valentina, 162-166).

Valentina knew that her mother was deteriorating rapidly and that her illness was irreversible. Realising that the AT could be used to preserve mementoes with her mother changed her views about the technology. Metaphorically speaking, the AT was no longer used as a 'shield' and perceived as a 'lawyer'. Instead, it was used as a 'keepsake box' and perceived as a 'mediator'. These new multiple uses were interpreted as acceptance of the AT. It could be argued that when Valentina discovered the versatility of the AT (it had multiple purposes) and acknowledged the long-term positive impact it had on her life (such as the storing of mementoes), she decided to accept it. This was a massive change as the technology brought personal and emotional value to her. Furthermore, Valentina had to confront one of her siblings since she saw through the camera that she did not feed or clean her mother properly. This led to a confrontation that revealed the use of the hidden camera and baby monitors, exacerbating the situation. A five-year legal fight began among them, which included lawyers for the breach of trust, as they were monitored without their consent. Valentina protected herself by showing the lawyers the recordings of the alleged events for which she was sued by her siblings. Her mother passed away in the midst of the legal

battle. She broke down on several occasions during the interview as reliving the memories caused her pain. In her story, she explained that the biggest difficulty of the illness was the aftermath with her family. She lamented the **irreconcilable family differences** and not the illness itself. She explained how at a point she was exhausted from all the *family conflicts*.

"I could have had her cremated or had her organs removed, but I did not want to go into more conflicts [with siblings] because we had already started with the legal problems" (Valentina, 261-263).

After 15 years of being a caregiver, Valentina was exhausted. The death of her mother did not bring peace to her family; only more conflicts. Now the family's focus was to distribute their mother's inheritance and to conclude the outstanding lawsuit. The combination of both events affected the physical and mental health of Valentina. The impact was so negative that Valentina, at one point, *blamed the disease* for destroying her family.

"Yes, we [siblings] do not see each other anymore. In fact, it is very sad. I mean, if you're currently documenting yourself about Alzheimer's disease, you know it's known as 'the breaker of families' [term used only in Spanish speaking countries]".

Valentina had the need to blame someone or something for the breakup of her family. Her sadness overwhelmed her so much that she felt it was fair to blame the Alzheimer's disease. After all, her mother died of this disease and her family ended up fighting over the effects of the disease. There were many valid reasons for Valentina to feel enraged toward the disease. Her expression "*the breaker of families*" was a powerful statement that synthesises her anger towards the disease. She explained she heard this expression during one of her support group sessions. This phrase resonated with her since it accurately represented what dementia did to her family. Believing this socially constructed idea and connecting with people who felt the same way helped her through her grief. At the time of the interview, she still had a poor relationship with them. She confessed that none of the siblings were talking to each other either as too many painful situations occurred during this period of time. The table 4.3.7.1 below summarises Valentina's account.

Superordinates	Subordinates
Influence of cultural values	Unfair distribution of roles Sense of fulfillment
Changes after the diagnosis of dementia	Double-care responsibilities Abrupt changes in her habits Manipulative behaviour
Misinformed about dementia	Lack of information Willingness to learn
Appropriate technology pragmatically	AT to engage in covert surveillance AT used for medical appointments AT was used to store mementos
Irreconcilable family differences	Family conflicts Blamed the disease

Table 4.3.7.1 Summary of Valentina's idiographic analysis

Table 4.3.7.2., is a small sample from the analysis of Valentina's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.7.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Transcript	Initial Noting/Exploratory notes	Semantic Content	Line	Emergent Themes	Super-ordinate Themes
They were closed-circuit cameras that we installed in her room and we had the main circuit in my husband's business. But later, we also used baby monitors and walkie talkies to speak with the people who were caring for my mum[at times].	Used a combination of technologies to care for her mother	descriptive	4-8	Practical/pragmatic appropriation of technology	Pragmatic appropriation of technology
We were twelve siblings, 8 women and 4 men. So, mainly the women were the ones that cared for my mother during the day. And at night, just one of my sisters, who is single and me. We were the ones who took care of my mum.	Females in her family assumed the role as carers. Single women are full time only because they live in the same house with their mother.	descriptive	8-12	Woman as carers	Machismo
They[cameras] were black and white and had sound. They could move from side to side. It covered the entire room very well.	Capable of describing the functionalities of the camera.	descriptive	16-18	Understands technology functionalities	
The reason why we put the cameras was for my mum's safety	Technology was implemented to monitor siblings when caring for	linguistic	27-29, 33-38	Technology to monitor	Technology used to exert control

Table 4.3.7.2. Sample Data Analysis from Valentina

Reflective Box

Valentina's interview was a tense experience for me. I remember having a bad experience driving to her home because it was located in an area where parking places were limited. This situation made me irritable because I had to walk with all the research equipment on the street for what seemed to me like a long time. She welcomed me to her home and directed me to her living room where I started making small talk with the purpose of slowly building rapport. Valentina gave me the impression of being a woman with a strong personality since most of her responses were opinionated, convincing, and goal-oriented. For example, I asked about her day and she responded:

Valentina: "Fine, thank you. I was able to finish all my work today on time, which gave me enough time to finish my book".

Researcher: "What was your book about?"

Valentina: "Have you ever heard of a book called 'The Help'? It is about the life of housemaids in the 1960s".

Researcher: "No".

I soon realised that with Valentina, building rapport was not an issue since she was very open with me from the beginning. However, I think that a challenge in her interview was how difficult it was for me to keep the interview centred on her experiences with technology. What I mean with this is that she spoke a lot about her relationship with her siblings. This gave me the impression that she really wanted to speak only about them. I had to, at least three times, change the subject so that I could ask her more about the technology. I was impressed with Valentina's openness with me. I personally think that she wanted to speak to someone neutral about her experience since she needed to be heard without judgment. I based this interpretation on how much detail she shared with me about her personal life, even though I was just a stranger to her. I chose Valentina's interview because there was a uniqueness in the way she appropriated technology. I feel that her history reflects how a human being can adapt a piece of technology to their changing needs.

During the analysis of her case, I had to revisit the initial feelings of irritability that I had previously disclosed. I had to analyse her case without judging her harshly as a result of my feelings. It was difficult because at first; I had established that Valentina was a person who was trying to portray herself as a person who was unaffected by the experience. This really frustrated me because after reading her transcript and hearing her audios multiple times, I was sure that I was judging her unfairly only because I could not understand the way she processed her pain. With this, I mean that because I did not see tears, hesitations, and remorse, I interpreted her as an ill-intentioned human. However, I think that I was constrained by this idea (namely, that she was playing the victim card) because so far, my other participants showed their emotions through tears. I thought that was a consistent pattern. Valentina's case was a great lesson for me as a researcher because now I understand that not all behaviours are universal and I need to consider contextual factors. On a last note, fast-forwarding to when the interview ended, I went back home and read the book synopsis (from the book she shared at the beginning of the interview). In my opinion, this was a feminist book with a depiction of what abuse, hate, and dependence meant for African American women of that time. In retrospect, I think Valentina was attracted to the book because, to a certain extent, it resonated with her experience. I argue that she strongly identified with the injustice of women being treated unfairly. Taking into consideration this small interaction at the beginning of the interview was a key element to my understanding of Valentina's account. Before, I just saw the facade she was showing the world, but then I was able to see how she had to pretend she was fearless to rise above the traumatic experiences she had as a caregiver.

Findings from Valentina's account

The following are the key findings from Valentina's account

- Valentina can place an emotional purpose to her AT (e.g. store memories).
- Valentina used the recordings from the surveillance camera for medical appointments as evidence of her mother's health.
- Valentina used the AT as evidence in a legal case.
- The double-care responsibilities increased Valentina's perception of caregiver burden.

4.3.8 Gloria's account

Gloria was a very welcoming and family-oriented woman. In the early 2000s, Gloria's mother started to display erratic and inexplicable behaviours. Seeing her mother's progressive deterioration brought an enormous amount of stress into her life and she could not understand what was happening to her mother. For example, her mother placed meat under her mattress and her shoes in the refrigerator. She also explained how her mother used to scream at the top of her lungs that she wanted to go to her home when she was already there. Gloria was very confused by her mother's behaviour as she appeared to be in perfect physical health. As her concerns grew, she told her siblings about what she had been noticing. Everyone was in denial but agreed to take her mother to a doctor for a professional evaluation. After countless visits to different doctors, her mother was diagnosed with Alzheimer's disease. With her siblings' approval, she decided to look after her mother in the mornings and hire nurses for the night. Her story reflects the **impact of cultural values** on her caregiving experience. These values shaped the way she saw the world and affected her decision-making process. For example, Gloria's family had *accentuated gender roles*.

"At first they said [my brothers]... 'that's a woman job', right?" (Gloria, 159-160).

...the women were there [with mother] and the men were just like, "OK, I'll buy that" (Gloria, 144-145).

Gloria had three brothers and two sisters. She described how, in her family, the women were in charge of all the caring responsibilities and the men took responsibility for all their mother's expenses. The first quote exhibits how her siblings were displaying behaviours that are consistent with the value of machismo, namely, women should be the ones providing care. With the second statement, the assigned roles became clearer; the women were physically and emotionally contributing to their mother's caring needs, whilst the men were communicated about what to purchase. The family was working as a team with assigned roles and a leader, namely Gloria. She was in charge of the decisions that concerned their mother since she assumed the role of primary caregiver. In her story, having these roles worked for them as a family because these behaviours were compatible with their embedded cultural values. Gloria was aware that her brothers were in a comfortable position since they only had to provide with money. Yet, she was relieved that she did not have that responsibility because Gloria was a housewife and therefore, if her brothers had not provided, she would have had to ask for money from her husband. This then would have been problematic and burdensome. Furthermore, she also detailed how she had been very close to all of her family members since her childhood, especially her mum. Gloria appeared to have a healthy relationship with all of her family, as she praised many of them throughout the interview. She explained that her family was her pillar and that she would do anything for them.

“And that made the family unite even more, despite the fact that Alzheimer’s is a disease that disrupts families, here it united us” (Gloria, 580-581).

This statement synthesised how Gloria perceived her *family* as a fortress. She believed her family to be strongly united and nothing could disrupt this. She expressed this wholesome characteristic with pride and knew her family would protect each other no matter what. Gloria believed her family got through the painful experience by helping, respecting and listening to each other. All these traits could be attributed to the value of familism. Her family prioritised their mother and worked in harmony. Another strong value in Gloria’s life was spirituality. Gloria’s religion (namely, Catholicism) formed specific views about life that helped her through her caregiving experience. For example:

“I believe that God our Lord was guiding us [family]...” (Gloria, 642-643).

“...[if only] more time would have been granted to us [family] and God our Lord would have allowed us to have her [mother]” (Gloria, 794).

“And then everyone [people at the funeral] there was [praying] inspired by the Holy Spirit. Then we [siblings] said ‘mummy leave in peace; everything will be fine. Here you fought a lot, it’s already your moment’” (Gloria, 694-696).

Gloria’s faith influenced her views about how to lead her life and accept death. This could be seen in her quotes which emphasised her trust in God. In particular, her word selection “*God our Lord was guiding us*”, “*granted to us*” and “*the Holy Spirit*” supported the argument. Her faith in God was interpreted as her coping mechanism because it provided her with guidance, relief because God allowed her mother to live such a long life, and a reason to believe that her mother’s passing occurred because God called her. Notwithstanding this, she still found it difficult to **make sense of dementia** because, at that time, there was not much information available in Mexico. *Adjusting to the diagnosis of dementia* was a big challenge for her because she was confused by all the sudden changes in her life. She described this as follows:

“Well, much sadness, I did not know what was waiting for us because we [siblings] had never heard of it [dementia]” (Gloria, 461-462).

“You ask yourself, what is going on? I mean no, no, no. Why? What is happening to me?” (Gloria, 319-320).

These two statements denoted the uncertainty Gloria felt whilst adjusting to her new responsibilities. She felt confused because there was not a single test that could tell her what triggered the disease. She could not understand why her mother developed Alzheimer's disease. The second quote showed the state of denial that Gloria went through before she assimilated the diagnosis. She also expressed that one of the most difficult adjustments was to accept that her mother was going to get worse in time.

"The roles are inverted, now you are taking care of her as a child, right?" (Gloria, 516).

Gloria saw this transition as unnatural. She was upset that her mother's essence was slowly fading away. It was painful enough for her to assume the role of caregiver, but now she had to treat her mother like a vulnerable child. Her role became a burden because she was dealing with many responsibilities but emotionally she was grieving. Furthermore, Gloria expressed *misperceptions about dementia*.

"People with dementia are all the same. Right?" (Gloria, 88)

"When a person with dementia enters the hospital [for a procedure] they change... they progress into another stage [of dementia]" (Gloria, 176-177).

All these prejudices clouded her judgement during her caregiving experience. Gloria assumed two things with these statements: 1) all people with dementia experience the same symptoms; and 2) medical procedures accelerate the progression of dementia. These assumptions were interpreted as Gloria understanding the disease through her own experiences. She did not have any formal training in caregiving, nor did she have anyone close to her (such as friends) who were going through the same situation. Therefore, she was learning through experience. Furthermore, Gloria also explained the multiple **negative outcomes of her caring role**. For instance, she developed a *sense of insecurity* towards other people's opinions.

"...we always had to be very careful with hospital nurses because it was very sad that they believed she [her mother] was a normal person" (Gloria, 180-182).

"When my mom who had Alzheimer's died [hospital nurses asked] 'How did she die? Your mom had Alzheimer's?' Well, yes, but we hid it [dementia] by taking good care of her appearance" (Gloria, 187-188).

To Gloria, it was important to hide her mother's illness from the world. She feared being judged and losing family friends. She believed people would not understand the disease since dementia has an attached stigma. Gloria used makeup and fine clothes to improve her mother's appearance. This action was interpreted as an attempt to protect her mother and her family from the outside world. This means that Gloria feared being judged by her caregiving skills. She thought that by keeping her mother's appearance impeccable, people would not suspect and if they did, at least they would perceive Gloria as a good carer. As Gloria's mother's dementia progressed, so did her dependency on her. This brought abrupt *changes in her emotional state*. For example, she expressed frustration every time her mother became aggressive.

"...sometimes there were very aggressive days because she would wake up aggressive and you have to change the medication and observe what you gave her because she had already gone to the doctor and they [doctors] always made changes and for example, she could not say 'it hurts here'" (Gloria, 295-298).

Her mother's behavioural changes brought an enormous amount of stress into her life. She had to make sure that she could provide proper care for her mother and protect her from harming herself and others during her aggressive episodes. Gloria's quote could be interpreted as stress. This was assumed from the noticeable tension in her voice (based on the audio recording). She also described feelings of burden.

"The problem of a person with Alzheimer's disease as the book 'the 36-hour day' states, it takes 36 hours from you" (Gloria, 293-294).

Gloria was implying that her role as a caregiver is burdensome because it is unpredictable. She thought that she never rested since her mother was constantly reacting to her environment and medicines. Her expression *"it takes 36 hours from you"* suggested that her role surpassed the limits of a full-time job or even a regular 24-hour day standard. Her social life and personal time with husband and children were reduced and restricted by her demanding caring role. Gloria worked mornings caring for her mother and it was very common to receive calls at midnight from the night shift nurses asking for help as they could not control her mother. Gloria felt trapped and decided to ask her siblings for help. They made the joint decision to buy an emergency button for whoever was near their mother. This technology was connected to the emergency services and all of her sisters. This lifted pressure off Gloria's shoulders as she knew her mother would receive medical attention in case of a real emergency. Even though she found a technological solution to aid her during her role as a carer, it took her a long time to **accept the AT**. For example, it was difficult for Gloria to describe and understand the AT.

"The other one was the piece that she had in the shower, it was like a push [button]... like an alarm" (Gloria, 77).

"It [the AT] was a like a button, it was a chain too and it was like a heart. So, it was like a heart shape and in the centre [i.e., resting at the chest height], there was something round, red and if the nurse pressed it, the call was triggered immediately" (Gloria, 31-34).

Gloria appeared to be technologically illiterate since it was difficult for her to express the way the ATs functioned. She relied on basic descriptions and comparisons to other objects that were familiar to her. For example, she used the term, "*the piece*" to refer to the emergency button and "*like a push*" to the action that activated it. Her technological knowledge was limited; she attempted to describe the AT using many adjectives (round, red, and looking like a human heart) to compensate for her basic descriptions. These were interpreted as the *abstract impressions of the AT* that Gloria had developed through observation. Gloria described all her previous experiences with the ATs used for her mother's care as positive. However, before adopting the technology, Gloria and her siblings felt *uncertain about the ATs' benefits*.

"We [siblings] did not know if it [the AT] was going to work for us" (Gloria, 705-706).

"...but we [siblings] never thought that this [emergency] button was going to give us a solution. For us, or at least for me, it turned out to be something wonderful" (Gloria, 718-720).

Gloria and her siblings felt doubtful about the reliability of the device. She was particularly worried that the device might fail to work in the middle of an emergency, and as a consequence, delay medical attention for her mother. Gloria explained that before the adoption of the emergency button, the procedure during an emergency or accident was to first call the emergency services and then call all the siblings notifying them about the situation. If an emergency occurred during the nurse's shift, she would first have to try to assist their mother, call emergency services, get the notebook with the siblings' numbers, and call them. From this, it can be seen that adopting the AT reduced the burden of making calls and allowed the person to focus directly on the person who needed assistance. The family was able to test the AT prior to implementing it into Gloria's caring routing. All of the siblings were very pleased with the functionality and ease of use the AT provided. Once it was formally adopted by Gloria and the nurses, she began to feel less burdened. She then proceeded to describe how her opinions about the AT evolved into full acceptance.

"It [the AT] was an immediate help and it was something for when my mom was very ill because we [siblings] knew that we had to be with her and we knew that this was going to be something [brief pause] ... fast (Gloria, 725-726).

“Very comfortable! It [the AT] is very easy [to use]!” (Gloria, 826).

In this case, the previous statements suggest the AT surpassed Gloria's initial expectations. She was able to fully *trust the AT* because it was proven to work in a reliable way. The AT covered all her needs, namely reducing response times and communicating fairly the incident to all siblings. Her description as “*an immediate help*” and “*fast*” reinforces this interpretation. It was noted that Gloria felt very fond of the AT since she even nicknamed it “*the heart*” (Gloria, 5). The following are three examples show how Gloria used this nickname on a regular basis.

“The nurse was..um..she had the heart ... if it was the next nurse's turn, she changed it”(Gloria, 14-15).

“...there were two times that by mistake she [the nurse] press the button of the heart, that activated it and immediately the calls came in. And then she immediately said no, that there was not an emergency, that it was a false alarm” (Gloria, 16-19)

“...that little heart [the technology] was the best, it was what the nurse brought if my mum fell or fainted or had low blood pressure, right? Then it was like an incentive for us [siblings].” (Gloria,11-12).

This new ‘pet’ name suggests she felt a connection, in a metaphorical way, with the AT. This means that Gloria referring to the technology as ‘the heart’ was her seal of approval because the chosen nickname conveyed a feeling of endearment towards the AT. The table 4.3.8.1 provides a summary of Gloria's account.

Superordinates	Subordinates
Impact of cultural values	Accentuated gender roles
	Family as a fortress
Make sense of dementia	Adjusting to the diagnosis of dementia
	Misconceptions about dementia
Negative outcomes of her caregiving role	Sense of insecurity
	Changes in her emotional state
Accept the AT	Abstract impressions of the AT
	Uncertain about the ATs benefits
	Trust the AT

Table 4.3.8.1 Summary of Gloria's idiographic analysis

Table 4.3.8.2., is a small sample from the analysis of Gloria's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.8.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 18
Time: 1:30
Total lines of transcript: 899

Transcript	Initial Analysis/Exploratory notes	Semantic content	Line	Emergent Themes	Superordinate Themes
The heart	Nicknames technology "the heart"	descriptive	5	Fond of technology, warmth to technology, liking of technology	Trust in technology.
We took care of my mummy	the task of caring was for all the brothers	descriptive	6	self-belonging	The family as a unit.
We	Collective-group identity	linguistic	6	group-identity	The family as a unit.
Then I took five minutes to arrive and the other people arrived in three minutes and in a minute.	Reason why she changed the order of the emergency contacts.	descriptive	9,10	Defensive attitude	Sense of insecurity.
...that technology was the best, it was what the nurse brought if my mom fell or fainted or had low blood pressure, right? Then it was like an incentive for us.	Benefits of the technology in her life	descriptive	11,12	Benefits of the technology	Comprehension of the technology.
The nurse was..um..she had the heart ... if it was the next nurse's turn, she	Everyday routine with the technology	descriptive	14,15	Adapting to new routine	Making sense of dementia.

Table 4.3.8.2. Sample Data Analysis from Gloria

Reflective Box

Gloria's interview was the longest interview, making its analysis a big challenge to me as a novice researcher. Her lengthy responses generated a generous amount of data that was complex to analyse. Gloria welcomed me to her home where she had prepared a room with two chairs and a small table, to make our interview as comfortable and private as possible. This was the only participant who showed great interest in the interview. My first impression of Gloria was that she was a calm woman with a devotion to Catholicism. I assumed this because her house entrance and the room where the interview was conducted were filled with religious figures, crosses, and numerous bibles. Her home reminded me of my grandmother's home which had a similar religious ambience. Gloria was very open with me about her experiences with the technology she used and her feelings during her time as a caregiver. I had no difficulty making her open up but I think my reactions to some of her responses affected the interview. For example, I noticed that she always referred to her mother as 'mummy'. In the first part of the interview, I thought that was endearing. However, when I noticed that this constant repetition was not an accident, I struggled.

Researcher: "Do you think that your mother noticed the technology?"

Gloria: "My mummy? Mmmmm... [makes long pause]"

Researcher: "Yes, your mother..."

Gloria: "I think my mummy knew that it was..." (106-109).

From this example, I would like to clarify two things: 1) I found it strange that a woman in her late 50s would refer to her late mother as 'mummy'; and 2) I have to acknowledge that my facial expression might have given away my complete bewilderment. These two developed opinions had to be revisited during the analysis of her account. I wanted to understand why that expression created a big impact on me. In order to address it, I identified all the timestamps of her transcript where she mentioned that word. Then, I listened to those specific parts from the transcript to identify Gloria's tone and any hints of emotions. Also, I was trying to see which feelings I had when hearing her audio again. For what it is worth, I had neutral feelings and reactions when I heard the 'mummy' extracts. The last thing I did was to find any other entities that were addressed with endearment in her transcript. To my surprise, she referred to all other people with regular nouns: brother, sister, father, nurses, and so forth. The only other entity with an endearing name was the technology, which she called 'the heart' or 'my heart'. I found that strange but also amazing since it opened another door for my analysis. During the analysis, placing all the emergent themes around a flat surface and being able to visualise Gloria's case, I realised that there was a similarity between her use of 'mummy' and 'the heart'. Both were used to describe positive experiences, whilst all the other entities (namely, siblings, father, and nurses) were described with negative or unpleasant experiences. For example:

Positive experiences/memories:

"I miss my mummy a lot; she was a nice, typical mummy who always gave you good advice" (Gloria, 565).

"I used the heart because it was something wonderful" (Gloria, 5).

"That little heart was the one that helped me care for my mummy properly" (Gloria, 20).

Negative or neutral experiences/memories:

"I was in favour of having cameras, my brother was not... My brother was not very happy that we would invest money in cameras." (Gloria, 790, 793).

"I was the last one [to arrive], so when my sisters arrived I was questioning, "why?" Well, it takes me time to arrive, so I decided to call the agency where they hired the service and asked them to divert the phones" (Gloria, 60-62).

Based on this, I was able to understand Gloria. At the beginning of the interview, she stated that she was very close to her mother before the diagnosis. Witnessing the progressive cognitive decline of her mother was emotionally painful for her. All of her family helped her but she felt that her mother needed more protection. By protection, I mean keeping her mother safe 24/7. Discovering the emergency button was 'wonderful' to her because with this AT, professional care (namely, medical doctors) would assist her in case of an emergency. Therefore, Gloria felt pleased and content with herself because she was able to provide what she considered adequate care with the AT.

Findings from Gloria's account

The following key findings were derived from Gloria's account.

- Gloria did not perceive the distribution of gender-based roles to be wrong (i.e. women care and men provide).
- Gloria's family became her support network making her perceive less caregiver burden.
- Gloria used her faith as a coping mechanism.
- Gloria's levels of caregiver burden increased when she felt that the parent-child roles were inverted.
- Gloria felt an emotional connection (i.e., endearment) to the AT.

4.3.9 Margarita's account

Margarita lived with her parents until the day she got married. It was easy to perceive the admiration she had for them. Using only flattering words when referring to her parents and in a very articulate manner, Margarita explained her feelings and thoughts around her caregiving experience. She explained to me that it was very difficult for her to be away from her parents for a long period of time. As a consequence, she settled down next to her parents' home with her husband. They all enjoyed a very healthy family relationship, full of regular reunions, parties, and trips. It all changed when Margarita's father passed away and her mother was left alone in her home for the first time in more than 30 years. As the years went by, she noticed a significant decline in her mother's cognitive functioning. She thought this was normal at her age and also believed it was because she missed her husband. One day, Margarita was visiting her mother and realised that common objects like spoons and plates had disappeared from the house. She grew suspicious, but later on, found them all cluttered in her mother's wardrobe. She was shocked by this, and by her mother's denial. Weeks went by and more objects disappeared. That was the moment when she decided to call her siblings for a family meeting and take action. Unanimously, they decided that her mother needed to pay a visit to the family doctor. It took various doctors in different specialities and multiple tests to diagnose Alzheimer's disease. Moreover, Margarita illustrated how she felt confused and scared about the diagnosis as she had never heard of the disease before and she had no idea how to help her mother. Margarita was a woman that was influenced by **core values and beliefs** that impacted her decision-making process. A statement to that effect is how she voluntarily assumed the role of primary caregiver. She felt that it was her duty and an honour to care for her mother. She described her stance about caring for her parents.

"I was the youngest of six siblings, so I see the experience of caring [for parents] as a way to thank them for all the sacrifices they made for me at some point. It brought me joy" (Margarita, 462-464).

"They [parents] made the decision to live next to my place voluntarily. When I got married, I asked my husband to grant me my wish of caring for my parents when they were of old age. So, I had a deal with him about this from the beginning" (Margarita, 363-365).

Being the youngest of six siblings, Margarita was raised by parents who had plenty of experience and financial stability. Margarita's family practised Catholicism and followed Christian values. She described her childhood as ideal because her parents were generous and understanding. Growing up, she had her parents' attention since most of her siblings were already married or studying away from their hometown. Therefore, she grew up having a close relationship with her parents. Based on these facts, it made sense that Margarita *prioritised her family*. She was raised with Catholic values and beliefs that encouraged love, respect and honouring one's parents.

Margarita genuinely felt joy when being around her parents and was truthful when saying she wanted to care for her parents. She explained the role her *spirituality* played on her during her caregiving experience.

“God is asking me to help families and sick people” (Margarita, 419).

“Speaking of faith, when I was praying at church, I could clearly hear how our Lord said to me: ‘The experience was not for you, it was for you to share it with others” (Margarita, 423-425).

These statements suggested that Margarita believed God gave her the task of being a carer as a way to inspire others. To her, being a caregiver gave her life a purpose. When Margarita said, *“God is asking me”*, it meant that she felt a calling and/or mission from God. In her second statement, she described how she ‘clearly heard our Lord’, which is another way of referring to the Christian God. From an objective perspective, the message she allegedly heard might be her inner voice (or conscience) or inner guidance (or intuition). From a biblical viewpoint, the voice she heard could be interpreted as God speaking to Margarita through prayer. In addition, God’s voice could only be perceived when living a Christian life. Margarita also explained how her Christian views aligned with her role as a caregiver.

“They [people with dementia] are chosen by God, that is why every time that I speak with other caregivers, I tell them to see the lesson behind the disease. One doesn’t choose this. When you get it [dementia], it is because there is something that the family and carers need to learn in life” (Margarita, 465-468).

“Now every time that I help a family, I feel like I am earning a gold coin and my parents are being showered with gifts in heaven” (Margarita, 472-473).

Margarita believed that God gives dementia to people that are part of a family where there is a lesson to be learned in life. It was assumed that these life lessons echo Christian values since they are being allegedly appointed by the Christian God. Therefore, her rationale suggested that God is, to a certain extent, punishing the family and not the person affected with dementia. In her second statement, Margarita implied that by helping others during their caregiving experience, she was earning an indulgence from God (a gold coin) and her family are being favoured (showered with gifts) by God. Margarita’s specific views about dementia were influenced and motivated by her faith. Hence, it could be suggested that Margarita was driven to be a carer because she wanted to earn her place in heaven by obeying God’s instructions (his voice). Furthermore, Margarita’s story indicated that there were positive and negative **effects of the caregiving experience**. The positive ones were the *inner strengths* that one developed as a caregiver like resilience, patience, and multitasking. For instance, she shared:

"It [caregiving experience] united us as a couple, as a family, and now as an Alzheimer's disease association. It inspired me to help because my testimony is way more important than all the books in the world as I lived it and that changed my life forever" (Margarita, 307-310).

Margarita wanted to make her experience as a caregiver an example to other carers in the same situation. She believed that by sharing her story, people could find it relatable and through the similarities, learn new ways to approach their experience as caregivers. Margarita's new approach resulted in a vibrant positive outlook on life that reinforced her new acquired inner strengths. She also described how her creativity developed since becoming a carer.

"I used to play bingo with her [mother] and I did the bingo [out of cardboard] with family photos of her grandchildren because she forgot them" (Margarita, 232-233).

Conversely, the negative effects were *beliefs about her mother* and formed ideas about the disease. For example, Margarita explained how she was convinced that her mother, despite her cognitive decline, saw her as a source of security.

"She [mother] did not know who I was. She did not recognise me anymore, but with just looking into my eyes, she knew that everything was fine. She knew that I was someone who loved her very much and that gave her that sense of security" (Margarita, 256-258).

"...because she didn't know how to be without me. I was her security" (Margarita, 259-260).

Margarita's quotes suggested that she viewed herself as her mother's protector. This assumption stemmed from the fear Margarita had of being forgotten by her mother. She expressed having a special and unique connection (for example, communicating with their eyes) with her mother that transcended her cognitive decline. Margarita's belief could be interpreted as a defence mechanism. Her subconscious was trying to protect her from the possibility of being hurt by the rejection from her mother. In a similar vein, Margarita's creative mind formed *impressions of dementia* based on her interactions with her mother and the beliefs around her. For example, she explained:

"People with Alzheimer's disease are sad because they cannot fight against the disease. And it feels like they want someone that understands them and gives them what they need" (Margarita, 270-273).

"I also placed post-its with phrases like 'you will never be alone, we will always be with you, do not be afraid'. Because they [people with dementia] are very afraid" (Margarita, 235-236).

The previous examples exhibited Margarita's interpretation of what people with Alzheimer's disease need. She believed that sadness and fear are a result of the affected person's need to be understood and treated with compassion. She did not disclose how she formed that impression, however, it was assumed that she did this through observation. Her expression "*cannot fight against the disease*" from the first quote and "*you will never be alone*" from the second, suggested Margarita was projecting her own fear and sadness of being forgotten by her mother. She felt that Alzheimer's disease was unbeatable since she could not find a way to stop the progressive decline. Margarita also placed post-its with reassuring messages because she was afraid of losing the last strand of the mother-daughter relationship that once was so strong. In retrospect, she was anxiously anticipating her mother's irrepressible deterioration. As the disease progressed, Margarita displayed symptoms of **caregiver burden**. She confessed she could not control *overwhelming feelings* of depression, anxiety and loneliness.

"It was difficult and horrible, but I had to set a limit as they [siblings] were abusing me. It was a very comfortable position for them [siblings]" (Margarita, 394-395).

Margarita believed her siblings were taking advantage of her well-intentioned wishes to care for their parents. When she expressed her siblings were in a "*comfortable position*", she meant it in two ways: 1) her siblings were very supportive because with their arrangement (Margarita being the primary caregiver), they did not endure any stress; and 2) in case of an unforeseen circumstances or legal issues, all the blame would fall onto Margarita. These formed views increased Margarita's perceived caregiver burden. Notwithstanding this, Margarita decided to inform her siblings about her hardships.

"Yes, they [siblings] were speechless. The truth is that I told them that I couldn't handle this anymore by myself. That I understood that they were all busy, but that I couldn't cope with this burden anymore" (Margarita, 375-376).

Margarita thought that by explaining her burdensome feelings with her siblings, she would receive empathy and compassion. She hoped they would understand how the role was affecting her, and as a result, responsibilities would be distributed fairly. However, the response she expected did not happen. Her siblings argued that they all had very busy lives and that they could occasionally help. Their decision brought more stress into Margarita's life because she could not comprehend why her *siblings refused to help*. She described how this painful realisation affected her life.

"My children saw me and knew I was sad and depressed. I was drowning. I couldn't cope with it anymore and my husband said that it [the experience] felt as if I was in the middle of a hurricane" (Margarita, 288-289).

"You don't rest, you don't stop. Believe me! That is why I understand when some families leave their family member with dementia tied up to a lamp post outside the hospital. It is just too much." (Margarita, 537-539).

Margarita's levels of perceived caregiver burden were elevated to a point where it affected her health and the people around her. She described feelings with intense connotations like "*drowning*" and being in the "*middle of a hurricane*". Both metaphorical expressions suggest Margarita felt like she was swimming (carrying out her responsibilities as a carer) in a huge ocean with big waves (namely, sadness, fear, and depression) that were slowly drowning her because there was no life raft (or time to rest), a rescue team (her siblings), or even a boat (wider family) to help her stay afloat. She felt so desperate and overwhelmed that she felt the need to use metaphors to explain her profound feelings. Margarita's husband grew concerned about her wellbeing and suggested they hired nurses and purchase an emergency button to be worn around the carer's neck. None of her siblings complained about this decision. Margarita described herself as technologically unskilled but, even so, decided to acquire the technology to alleviate the burden she was experiencing. After months of using the emergency button, Margarita developed **feelings engendered by the AT**. For example:

"When you have a sick person, what you need is to look for tools that can give you peace and security. And the truth is that yes it was very good for me, I have nothing negative to say, on the contrary, whenever I can I recommend it [the AT]" (Margarita, 81-82, 85-86).

"Yes, yes, yes because... it made me feel at peace by knowing that if an emergency happened, I was not the only one responsible, as my siblings had already been informed at the same time" (Margarita, 121-122).

To Margarita, the AT provided a *sense of security* because she knew the emergency button was conveniently close to her (hanging from her neck) and programmed to call emergency services to assist her mother in case of an accident. In the past, she had to assess her mother's injury, then run to the phone to call emergency services and then call her siblings. Hence, the perceived convenience made her feel the AT gave her *peace of mind* because her mother's care was improved and siblings were equally responsible now. Moreover, Margarita realised she needed more things to balance the caregiving experience since having the emergency button and the help of nurses was not enough for her. She felt that in case of immediate assistance it would be

resourceful to seek help from any person in her house (she lived next to her mother's home) since she had five children that could run to their grandmother's aid. She bought and installed wireless doorbells for her mother's bedroom, bathroom, and living room. All these doorbells were programmed to ring directly to Margarita's home sound system to communicate an emergency. Reducing communication times during an emergency is an example of the immediate **benefit of appropriating the ATs**. Her improvised system intended to provide a technological support system to care for her mother. Hypothetically speaking, if an accident were to occur near her mother's bed, whoever was with her mother would press the emergency button (that is being carried on the neck by a chain) which would ring the doorbell that was positioned on her mother's bed rest. In this scenario, Margarita would be notified twice because she would receive a phone call and hear a ringing that would inform her of the incident. She programmed these doorbells to have a special sound so that she could distinguish them from the regular doorbell in her own house. She felt this system added an extra layer of safety, which *improved her mother's care*. She explained that the combination of these ATs increased her *independence*.

"I was able to have more freedom to do my own things. I love playing tennis, so I was able to play tennis and I could make my life again. It gave me freedom, independence" (Margarita, 124-125).

Margarita appropriating these two ATs brought rapid and noticeable positive changes in her life. Before she used to feel overwhelmed and afterwards she reported feeling free. The contrasting feelings suggested that appropriating the ATs significantly decreased her caregiving burden. She pointed out how the ATs *reduced her stress* since she was now able to regain her previous hobbies. It was implied that she felt free and independent because the AT reduced the need to have someone 24/7 next to the person with dementia. However, it might also be that the perceived caregiving burden decreased because her siblings were now involved and equally responsible. Table 4.3.9.1 below, illustrates the summary of Margarita's account.

Superordinates	Subordinates
Core values and beliefs	Prioritises her family
	Spirituality
Effects of the caregiving experience	Inner strengths
	Beliefs about her mother
	Impressions of dementia
Caregiver burden	Overwhelming feelings
	Siblings refused to help
Feelings engendered by the AT	Sense of security
	Peace of mind
Benefit of appropriating the ATs	Improved the quality of her mother's care
	Independence
	Reduced her stress

Table 4.3.9.1 Summary of Margarita's idiographic analysis

Table 4.3.9.2., is a small sample from the analysis of Margarita's account. For more details about how the idiographic analysis was done step by step please see section 4.2.4. In Table 4.3.9.2, from left to right, it can be seen in the first column the transcript passage that was selected by the researcher as part of the initial analysis. The second column contains the exploratory notes and/or initial impressions that the researcher wrote when reading the transcript for the first time. The third column contains the type of semantic content: linguistic, descriptive or conceptual (these concepts are described in section 4.2.4 point 3). The next columns provide the line in which the transcript is positioned. The fifth column contain the themes that were emerging during the analysis and finally, the final column contains the superordinate themes from this particular participant.

Participant 10
Time: 1:05
Total lines of transcript: 545

Transcript	Initial Analysis/Exploratory notes	Semantic Content	Line	Emergent Themes	Superordinate Themes
It was like a heart, hanging from a chain.	Special attachment to the technology as it even has a nickname.	conceptual	4	Nicknamed technology	Appropriation of technology
And that heart had a button and the moment it was pressed it automatically made five calls to our[siblings] houses where it said that there was an emergency at my mum's house and that we should go and see her.	Difficult to describe how the technology worked, very superficial description.	conceptual	4-6	Unfamiliar with technical terms	Technologically unskilled
My mother had the tendency to take off everything she had on. She could not have a little necklace on as she would pull it off. This device had a chain so it would have been impossible for her to wear it.	Suggests that people with advanced dementia aren't suitable to wear devices as they will remove them.	descriptive	12-13	Disapproves wearable technologies for patients	
Actually when we bought it[emergency button], my mother was already in a terminal stage but she still walked. And several times she would have a fall and the caretaker at the time could not even reach the phone to dial for help and with the heart she just	The device came to change the way they handled their mother's falls. Now with the help of the button, the caregiver could stay with their mum as help arrived. Changed the way they addressed emergencies.	descriptive	13-16	Technology assisted during emergencies	Appropriation of technology

Table 4.3.9.2. Sample Data Analysis from Margarita

Reflective Box

Margarita gave me the impression of being a busy woman. I assumed this because finding a convenient time for our interview was very difficult. The day of her interview I was close to cancelling it because I had the flu. I remember waking up with a high fever and body aches. Her interview was scheduled for the late afternoon, giving me plenty of time to rest and control my fever. It was really challenging to me. I was constantly debating with myself whether I should cancel or not. Notwithstanding, I felt that if I cancelled, she would not give me a second chance to interview her since it was difficult to synchronise our schedules. Thankfully, her home was not far away so I did not have to drive a long distance feeling so ill. When I arrived at her home, I was greeted by a lady who directed me to the living room. I was told that Margarita was going to be late. She arrived 30 minutes later and we proceeded with the interview. With all this in mind, my first impression of Margarita was negative. This perception was affected by my illness and her lack of punctuality. During the interview, I noticed that Margarita was different in many ways to any of my previous participants. She was very well-spoken, intelligent, and feminine. With this, I mean that she appeared to be used to interviews and speaking about this subject since many of her answers sounded as if they were well-studied. Her hair and makeup were impeccable, her voice was soft, and she held her hands and crossed her legs like the queen (that is, she possessed a kind of royal etiquette). She was one of those people that when they enter a room, they immediately draw attention. Whilst the interview continued and I had more time to analyse her body language, my impression of her changed. She made me feel empathy for her. Margarita narrated her story with the use of many feelings, facial expressions, and hand gestures. It was very easy to speak to her because it appeared to me that she had already made sense of her situation. There were no hesitations, stutters, or pauses during the interview. One of the most powerful moments of the interview was when she spoke about her political views. Her views were emotionally charged and she was visibly passionate about this subject. I mention this specific instance because I think that it was the only time I saw her expressing anger. For example, when I asked about governmental support and nursing homes she said in an agitated voice:

"They [government] do nothing. If they see that the older adult is healthy they will deny medicines, but that does not make any sense since people with dementia are mentally disabled! They appear fine but they are not! The government just focuses on children because older adults are not going to last long and they are not contributing to the economic growth of the country. Preposterous! And don't make me start with the nursing homes. They are a complete joke! Nursing homes in Mexico are conditional. They ask you to only bring functional older adults. Basically, they only accept older adults who eat, shower, and use the toilet by themselves. But the rationale of this debate is that if I want to send this person to a nursing home, it is because I as a caregiver cannot deal with this anymore! You understand my frustration?" (Margarita, 517-527).

This caught my attention because at the very start she was very ladylike and during the political conversation, she changed her tone and pose. This made me assume that she was visibly affected by this on a personal level. In addition, during the analysis, I tried to review her audio several times to revisit and confirm my initial impressions. They all remained the same apart from the isolated event when speaking about politics. It took me a long time to understand Margarita. I had to bracket various things during the analysis. For instance, I was feeling ill and therefore many things were not perceived well since my senses were compromised. Lastly, after going through all the emergent themes and parts that caught my attention, I learned why Margarita reacted differently when speaking about politics. It was weeks later that I realised that her passion stemmed from a moment I had not considered relevant to be a theme. She explained to me how one day she was shocked to hear from a woman she knew that she had left a person with dementia tied up to a lamp post outside a hospital. She was shocked by the woman's motives. She told me:

"The woman said to me: 'Look Mrs., I don't have a job, I am going through a divorce, my son has a serious drug addiction, my daughter is being abused by her husband. I cannot deal with my father's illness at the moment. I am going insane. The government should help us. When I left him there, I was hoping the police would take him to a nursing home and pay for his care'" (Margarita, 539-542).

As a researcher, it was my fault for not noticing this. I ignored this because I did not identify this as relevant. When she told me this story we were not conversing about this topic. However, this isolated

event made me understand the anger she felt towards the lack of governmental support and the impact it had on regular citizens.

Findings from Margarita's account

The following are key findings from Margarita's account.

- Margarita's core values influenced her decision to assume the caring role.
- Margarita used her religion as a coping mechanism throughout the experience.
- The ambivalent feelings that Margarita had during her caregiving experience increased her levels of caregiver burden.
- Margarita developed feelings engendered by the AT.
- Margarita appropriated technologies because she was motivated to fulfil her own needs.

4.4 Conclusion

In this chapter, there was a presentation of the results from the idiographic analysis and the rationale behind it. Section 4.2 contained a detailed description of all the steps from the IPA approach that were followed for obtaining the results of this analysis. Section 4.3 contained an introduction of the key findings and superordinate themes that emerged from each participants' accounts. All participant's accounts included an in-depth exploration of their lived experiences based on their interviews and the researcher's personal diary. Illuminating quotes from each participant were used to narrate and interpret their experiences. A summarising table containing the emergent themes and bullet points highlighting the participant's key findings was exhibited after each account. Finally, the reader can conveniently locate a reflexive box, which contains the researcher's reflections and sense-making on the emergent themes from this analysis. Table 4.4 below, contains a summary of the cluster of superordinates that resulted from each participant as part of the idiographic analysis. In the next chapter, the results from the group analysis will be presented.

Participant	Superordinates
Sofia	<ul style="list-style-type: none"> Rationalising the diagnosis of dementia Effects of caregiver burden Emotional resilience Opinions about the technology AT served as a source of accountability
Claudia	<ul style="list-style-type: none"> Cultural expectations Caregiver burden Attitudinal changes Technologically insecure Positive effects of having an AT
Maria	<ul style="list-style-type: none"> Processing dementia Instilled cultural roles Appropriating technologies Effects of the caregiving role
Frida	<ul style="list-style-type: none"> Emotional reactions after diagnosis Assimilate the diagnosis Family influence Technology served as an assistant
Camila	<ul style="list-style-type: none"> Family problems Assimilating the diagnosis of dementia Psychological effects Technology as a positive influence
Pablo	<ul style="list-style-type: none"> Instilled values Uneducated about dementia Caregiver burden Emotional self-regulation Technology as an enabler of care.
Valentina	<ul style="list-style-type: none"> Influence of cultural values Changes after the diagnosis of dementia Misinformed about dementia Appropriate technology pragmatically Irreconcilable family differences
Gloria	<ul style="list-style-type: none"> Impact of cultural values Making sense of dementia Negative outcomes of her caring role Accept the technology
Margarita	<ul style="list-style-type: none"> Core values and beliefs Effects of the caregiving experience Caregiver burden Feelings engendered by the AT Benefit of appropriating the ATs

Table 4.4. Summary of idiographic results

Chapter 5: Results from the Group Analysis

5.1 Introduction

In Chapter 4, the results from the idiographic analysis were introduced. All the emergent themes that resulted from the previous chapter were utilised for this analysis (i.e., across case analysis). The aim of this chapter is to provide an explanation of the way the Interpretative Phenomenological Analysis (IPA) approach was used to conduct the group analysis. Section 5.2 consists of a description of the steps that were followed for the analysis. Section 5.3 contains an introduction to the results, section 5.4 exhibits the synthesis of findings, and section 5.5 comprises of a first-person reflexivity statement from the researcher to provide the details of the rationale behind the interpretations from this chapter's findings.

5.2 Analysis of the group

This section aims to present the steps that were followed to conduct the group analysis. The analysis consisted of comparing and contrasting all the superordinates themes that resulted from the idiographic analysis of each participant. Only superordinates themes were considered since they are the high level category (see Section 4.3), which stores the identified patterns (i.e. subordinate themes) into a synthesised idea, commonality or description. The aim of the group analysis was to identify patterns and important aspects between cases (i.e., from each participant) that would capture the informal caregivers' experiences. In order to achieve this, the researcher followed these steps (see Appendix 4 for photographic evidence):

1. The researcher printed, cut, and laid on a flat table all the clusters of superordinates from the idiographic analysis by participant.
2. The researcher looked for connections, similarities, patterns, and differences between the superordinates. Once patterns were identified, the superordinates were clustered together.
3. Once all themes were within a group, the cluster was then given a name. It is important to clarify that once the superordinate became part of a cluster, their category level changed to subordinate. This occurrence, as explained in section 4.3, happened because the newly formed cluster was assigned a representative name making all the superordinates lose their hierarchical level from high to low and transforming them into subordinates. Hence, the new name obtained the highest rank and became the superordinate. This new superordinate represented a shared commonality or was a suitable description for the recently formed subordinates. From this analysis, eight superordinate themes emerged from the participants' data. The following table, table 5.2a, displays the preliminary superordinates that emerged from the subordinates' themes (namely, the results from the idiographic analysis):

Superordinate	Subordinates
Hardships of the experience	<ul style="list-style-type: none"> • Effects of the caregiving role • Effects of the caregiving role • Caregiver burden • Attitudinal changes • Psychological effects of caregiving role • Symptoms of caregiver stress • Negative outcomes of her caring role
Assimilating the diagnosis	<ul style="list-style-type: none"> • Rationalising the diagnosis of dementia • Behavioural changes after diagnosis of dementia • Processing dementia • Changes after diagnosis of dementia • Emotional reactions after diagnosis • Making sense of dementia
Cultural influences	<ul style="list-style-type: none"> • Cultural expectations • Instilled cultural roles • Impact of cultural values • Instilled values • Core values and beliefs
Appropriating the technology	<ul style="list-style-type: none"> • AT served as a source of accountability • Technology served as an assistant • Technology as an enabler of car • Implemented a surveillance system • Improvised use of technologies
The influence of family	<ul style="list-style-type: none"> • Irreconcilable family differences • Family problems • Family influence
Opinions about the AT	<ul style="list-style-type: none"> • Accept the technology • Positive effects of having an AT • Feelings engendered by the AT • Technology as a positive influence
Emotional Resilience	<ul style="list-style-type: none"> • Emotional Intelligence • Emotional self-regulation
Uneducated about dementia	<ul style="list-style-type: none"> • Misinformed about dementia • Uneducated about dementia

Table 5.2a Analysis of the group

4. The next step was to place the subordinates belonging to each superordinate with the participant from which they emerged. Each allocated subordinate represented an occurrence (marked by an x). In accordance with the suggested guidelines from Smith et al. (2009, p.107), it was established by the researcher that the final superordinate themes would be those that had occurrences in more than half the sample. Since there was a total of nine participants, occurrences needed to be present in at least five participants' accounts. Table 5.2b represents the structure that has been used throughout this chapter with the results of the analysis. The aim of the table is to illustrate the headers that were used for each column. From left to right, the first column displays the preliminary superordinate themes that resulted from step 3. Then, all nine participants were allocated a column that is identifiable with a unique colour. The last column details whether the superordinate theme was present in over half of the sample or not. Each row from the table represents a superordinate theme. The subordinates that belonged to a superordinate were then marked with an "X" under the participant from whom they emerged. Thus, the "X" under the participants' column represents an occurrence. The final superordinate themes were highlighted in grey, whilst the discarded superordinates with fewer than four occurrences were left in white.

Superordinate themes	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita	Present in over half sample?
Hardships of the experience	X	X	X		X		X	X	X	YES
Assimilating the diagnosis	X	X	X	X	X	X		X		YES
Cultural influences		X	X	X			X	X	X	YES
Appropriating the technology	X		X	X		X	X		X	YES
The influence of family				X	X	X				NO
Opinions about the AT		X							X	NO
Emotional Resilience	X						X			NO
Uneducated about dementia				X			X			NO

Table 5.2b Results from the group analysis.

5.2.1 Results: The final superordinates

The previous section showed the superordinates that made it to the final stage. The final superordinates were selected because occurrences were identified in more than half of the participants. The aim of this section is to present the detailed results of the group analysis and the rationale for their final descriptive titles. Table 5.2.1 illustrates the final superordinate themes with respect to their corresponding subordinates.

	Hardships of the experience	Assimilating the diagnosis	Cultural Expectations	Appropriating the technology
Sofia	Effects of the caregiving role	Rationalising the diagnosis of dementia		AT served as a source of accountability
Claudia	Caregiver burden	Attitudinal changes	Cultural expectations	
Maria	Effects of the caregiving role	Processing dementia	Instilled cultural roles	Appropriating technologies
Frida		Emotional reactions after diagnosis, Assimilate the diagnosis		Technology served as an assistant
Camila	Psychological effects of caregiving role	Assimilating the diagnosis of dementia		
Pablo	Symptoms of caregiver stress		Instilled values	Technology as an enabler of care
Valentina		Changes after the diagnosis of dementia	Influence of cultural roles	Appropriate technology pragmatically
Gloria	Negative outcomes of her caring role	Making sense of dementia	Impact of cultural values	
Margarita	Effects of the caregiving experience		Core values and beliefs	Benefit of appropriating the ATs

Table 5.2.1 Summary of the group analysis results.

The subordinates in table 5.2.1 represent the patterns identified in each participant. Each pattern revealed a repetitive behaviour, process, expectation, or action of a participant. When comparing all the final subordinates against their allocated superordinate, the analysis revealed that some patterns were named similarly (for example, influence of cultural roles and impact of cultural values), but individually they were experienced differently by the participants. Since the aim was to identify the patterns of the participants' experiences with assistive technologies (ATs), the

current names/titles did not give justice to the meaning behind the results. Therefore, the final step before introducing the interpretations that led to the main findings of this research was the allocation of suitable names/titles to the final superordinate and subordinate themes. The steps followed for the refinement were:

- 1) The researcher merged all the subordinates that were named identically, had similar wordings, or significance. For example, in table 5.2.1 above, the column, 'hardships of the experience', has "effects of the caregiving experience" twice and other occurrences that communicate a similar idea, that is, symptoms of caregiver stress.
- 2) Once the subordinates were synthesised and grouped, the researcher went back to each case and selected the interview quotes that represented the main idea of their subordinates.
- 3) The researcher analysed all the quotes from the four final superordinate themes to identify the similarities and differences between the participants' subordinates. This was achieved following a double hermeneutic approach (as described in section 4.2.4).
- 4) The next step was to modify the names/titles of the final themes to represent in an authentic way the common traits from this particular group. The choice for the creation of new names/titles was the researcher's idea based on two things: 1) In the official IPA suggested guidelines from Smith et al. (2009) it has been stressed that there is not a one "prescribed single method for working with data" (pg. 79). In fact, they argue that researchers who use IPA should be "open-minded, flexible, patient, empathic and willing to emerge into the participants' world" (Smith et al., 2009, p.55). 2) The author realised that most of her participants found it difficult to express certain emotions and as a result often used proverbs, metaphors and so forth. Therefore, it seemed appropriate to pragmatically add this step as part of the creative nature of the IPA analysis. The aim of this naming was to maintain the essence of the commonality revealed in the participants' experiences. In some instances, metaphors, idioms, and sayings were used for the themes to clarify and/or simplify the complexities that the identified pattern entailed.

The following section consists of a description of the way each superordinate and subordinate themes names/titles were modified to represent the participants' lived experiences with ATs. There will also be a presentation of the interpretations of the final themes and findings from this study.

5.3 Findings from the Group Analysis

The aim of this section is to depict the authentic descriptions and interpretations of the participants' lived experiences with ATs for their caring role. The findings of this analysis developed from the researcher making sense of the participants' sense-making of their experiences (see the double

hermeneutic approach in section 4.2.4). A total of four superordinate themes emerged from the group analysis. Each subsection contains a detailed rationale for the superordinate theme's new allocated title (as stated in step 4 from section 5.2.1), convergences and divergences from the group, and a summary with the key findings from the study. All superordinate themes will be described with their nested subordinate themes and illustrative quotes from the participants' transcripts. Each participant was allocated a colour that represented their voice within the interpretations. Throughout this section, the occurrence of each subordinate theme among participants is summarised in tables.

5.3.1 Superordinate 1: Hardships of the experience

The first superordinate theme, "hardships of the experience", had the nested subordinates that described negative feelings towards their role, effects of the caregiver experience, and caregiver burden. Table 5.3.1a below shows the participants who reported an occurrence that reflected an experienced hardship.

Superordinate: Hardships of the experience							
Participants	Sofia	Claudia	Maria	Camila	Pablo	Gloria	Margarita
Subordinates	Effects of the caregiving role	Caregiver burden	Effects of the caregiving role	Psychological effects of caregiving role	Caregiver burden	Negative outcomes of her caregiving role	Effects of the caregiving experience

Table 5.3.1a Summary of subordinates themes from Hardships of the experience.

The superordinate, "hardships of the experience," was too simplistic to represent the complex struggles that the participants reported. After synthesising the subordinates, three general ideas were revealed in the analysis:

- 1) Participants stated that caregiver burden was one of the main contributors that made them acquire an AT for their role. Participants who reported this occurrence were grouped together to form the subordinate "bearing the burden of care" since in this case, the participants were suffering the consequences of caregiving for the sake of their families.
- 2) Participants were affected emotionally by the inverted parent-child dynamic. To encapsulate the psychological distress this caused them, the subordinate was changed to "stuck with the caregiver role". The title represents the feelings of entrapment participants felt doing and experiencing their double care responsibilities.

3) Participants felt frustrated about dementia's unpredictability. The chosen name for this idea was "there is no quick fix for caregiving" because no matter how hard the participants tried to manage responsibilities or delegate them, they realised that people with dementia (PwD) were unpredictable and difficult to manage.

Dementia affected each participant's PwD in a different way, therefore, the dynamic nature of dementia made it difficult to set a routine or delegate responsibilities. To encapsulate correctly the aforementioned patterns, the superordinate needed a name that could represent the struggles of participants with a suitable name/title. Therefore, the superordinate's name/title was changed to "a silent battle". The new superordinate title reflects participants' inner frustrations (such as the inverted parent-child dynamic) and personal struggles (such as dementia's unpredictability) that triggered their need to acquire an AT for their caring role. The title "a silent battle" refers to how these participants explained how they refrained from talking about their feelings, worries, and frustrations they had about dementia to anyone else. They did not speak about the experienced hardships because they feared being judged, thought that nobody else cared about their problems, or simply that their family would not understand the pain they were going through. They kept silent because they wanted to reduce or prevent their family's stress since they had gone through enough suffering and worries dealing with the changes that dementia brought to their lives. The caregivers felt that speaking out about the constant state of confusion they were in would have brought side effects to the entire family. For example, some participants felt that if they asked for help, many of their siblings would have complained, making them fight about who does more, dividing the family, and potentially making things even harder for the caregiver and the entire family. The new name/titles are shown in table 5.3.1b. The first row displays the title of the superordinate theme and the following row shows the subordinates themes. Section 5.3.2 will contain the interpretations derived from this superordinate theme.

A Silent battle
a) Bearing the burden
b) Stuck with the caregiver role
c) There is no quick fix for caregiving

Table 5.3.1b The first superordinate with its nested subordinate themes.

5.3.2 Convergences and divergences of “a silent battle”.

It was stated in section 5.3.1 that this superordinate theme title reflected participants' inner frustrations and personal struggles that triggered their need to acquire an AT for their caring role. The aim of the following subsections is to present the convergences and divergences identified from the three nested subordinates from “a silent battle”. The subordinates themes were: 1) bearing the burden; 2) stuck with the caregiver role; and 3) there is no quick fix for dementia.

1a. Bearing the burden

Participants' experiences suggested caregiver burden was one of the reasons for purchasing an AT. Caregiver burden was explored in section 2.3.3 and described as accumulated stress resulting from caregiving duties. All these participants expressed feeling caregiver burden to different degrees as well as the need to remain silent. **Maria** and **Sofia** struggled with financial burden, that is, the monetary expenses and work-related adjustments that a caregiver has to endure to provide for the caring needs of the affected family member. Their accounts demonstrate how they experienced the same type of caregiver burden but in different ways. For instance, **Sofia** shared:

“As the disease progressed, expenses skyrocketed and my mum was with some nurses and many other problems started between us [siblings] about ‘it's your turn, it's not your turn’ which is something that I do not like. I told them ‘my mum is not a chore to me, I come when I want and I can” (Sofia, 202-206).

Sofia had to deal with the financial pressure of paying for all the expenses of her mother and children. Several of her siblings co-operated with some money, but they were not consistent. This situation forced her to work part-time to support and help her mother, children, and herself. This brought an enormous amount of stress that had an impact on her health. **Sofia** decided to remain quiet about this struggle because her siblings frequently gave her the cold shoulder whenever she texted or called them. She decided to deal with this caregiver burden by herself.

“When my dad started to get ill, his room was no longer used. The living room became his room. The sofa was removed; it was rearranged because there was a need to have a hospital bed. My dad was in a hospital bed. For us, it was easier because his room was small and just had a hospital bed and a set of drawers” (Maria, 78-81).

Conversely, **Maria's** family had to rearrange her father's home to fit his new needs. This unforeseen expense took her by surprise but with her family's support, they were able to provide for their father. The unity of their family was strengthened, but her caring responsibilities evolved as she had to manage all expenses and adapt to the new challenge. She decided to take control of all the following expenses to avoid asking for any other 'favours' (namely, financial support) from her siblings. **Maria** had full support from her siblings whilst **Sofia** did not. These two accounts reflect the divergence that existed between them under the 'same phenomena'. Both participants were theoretically experiencing the same type of caregiver burden but with a different intensity, therefore, the outcome translated into contrasting world views. Participants also reported physical burden, namely, exposing the body to highly demanding activities that can result in malnourishment, dehydration, or exhaustion, limiting the body's capabilities.

"The nights. The nights are difficult because he doesn't sleep continuously. He gets up to go to the toilet, he feels disoriented and says over and over again, 'I want to go to my house'" (Pablo, 256-257).

"It was a constant worry because she would wake up, go to the toilet, and sometimes fall. And sometimes I would tie her up, I would put her like a scarf, hand in hand [with her], and she would take it off. And I did not even notice until I saw that she was already standing. And I used to ask her, 'mum where are you going?'" (Camila, 221-224).

"Very exhausting. Unbelievable" (Gloria, 280).

"Yes, I started to develop hypertension. My blood pressure was very high and I gained a lot of weight because I was anxious all the time with my responsibilities" (Margarita, 402-403).

Pablo, **Gloria**, and **Camila** described being in the state of physical exhaustion, whilst **Margarita** expressed deterioration in her physical health. Both variants of physical burden suggest the constant deprivation of substantial human needs like rest, in the case of exhaustion, and medical attention for the participant who developed health issues. These examples demonstrated the divergence between their cases of the perceived physical burden. Additionally, for both kinds of physical burden, the participants expressed the need to remain silent to avoid becoming a burden to their family members. Finally, **Claudia** and **Sofia** indicated having a psychological burden in the form of emotional stress. **Claudia** described her experience as follows: *"It was horrible, like an odyssey"* (228). Her statement *"an odyssey"* (228) is an expression that refers to an

experience that is full of different events and emotions that change the way one's world is perceived, just as in Homer's poem, the Odyssey (Camps, 1980). She later confided, "**I went to psychiatric therapy because it relieved me**" (439, 443). Furthermore, **Sofia** was able to articulate the wave of mixed emotions she felt as a carer.

"Exhausted would be the ideal word. It is a physical, emotional exhaustion that you cannot describe with words because it is a mixture of feelings. You feel impotence because you cannot do much for them. Everything you try does not work. Sometimes it works for you to sing, pray to calm them down, and so on, but the next day it might not work. Then, this disease pushes you to invent, to be creative, to change your activities. Nothing works for you, even if you try to feed them in a thousand ways, they do not want to eat. Physically, it is tiring because they do not sleep and you do not sleep either. But the next day you try something new. I think the most exhausting part is the emotional part because you feel sad. I came to think that my life had no meaning. That's why I fell into depression because I said, "if this is what life is, then I don't want to live" and you definitely need help" (Sofia, 558-568).

It was clear that **Claudia** and **Sofia** experienced a degree of psychological burden. However, **Sofia** diverged from the other participants as she clearly expressed the different aspects of caregiver burden that she felt and the ways they affected her. This subsection explained the ways in which the participants experienced the same types of caregiver burden but at different degrees of intensity. It also showed that 'bearing the burden of care', in this analysis, signifies the ways in which the participants kept the suffering of the perceived caregiver burden to themselves, to prevent any conflicts and/or arguments with their siblings that would have created more stress for the extended family. They believed that if they expressed themselves, their siblings would minimise or underestimate their claims or it would even create a disagreement between siblings that would divide the family. These behaviours resonate with what was described in section 1.2.2 and 1.2.3 from this thesis were it is explained that there is no government aid for Mexican ICs, how their cultural values play a role in their decisions, there is a scarcity of nursing homes and the few ones that are available rarely accept PwD. It can be concluded with this subordinate theme that a finding for this research is that the accumulation of caregiver burden was a contributing factor for the participants to get an AT for their caring role.

1b. Stuck with the caregiver role

Participants reporting occurrences under this subordinate described feeling stuck with their caring role. Their feelings revealed confusion about the scope of their role since it appeared to be slowly progressing into more than just being a carer. The unpleasant feeling was reported as another contributing factor to acquiring an AT for their role. The following example focuses on how gradually, some informal caregivers (ICs) felt confused by the process of transitioning from being and behaving as the child of their PwD (their parent), to becoming their carer after the diagnosis, and finally themselves assuming the role of 'parent' for the PwD, given that at some point, a PwD will become completely dependent on their carer. The essence of the difficulties of this complex transition was well articulated by **Sofia**.

"I think it is a big responsibility to be your mum's mum. When my mum used to call me "mum", I would tell my siblings and they would laugh. And I said to them, "Well, it does make you laugh, but do you know what it means to be your mother's mum?" I'll tell you – it is to take care and watch over her whole life, it is taking care of her diet, her medicines, her safety, it is to be her eyes. I saw it as a huge responsibility. It was something that weighed on my shoulders, whilst they only saw her for three hours a week when they visited" (Sofia, 528-534).

Sofia expressed the feeling of being "***your mum's mum***". This statement shed light onto the moment she accepted that their lifelong mother-daughter relationship was over and had become inverted. To her, this new role was not natural and clearly crossed the boundary between being a daughter and a carer. She felt conflicted and confused because she was also being a mother to her own children and a full-time worker (see her account in section 4.3.1). Having double care responsibilities (namely, caring for her own children and her mother) made her question her identity as a mother, a carer, and a daughter. She was so absorbed by all the responsibilities that she did not have time to make sense out of it. She also thought no one would understand her situation. Other participants resonated with the feeling of entrapment with their double care responsibilities and felt that they were pressured into their role.

"At that time my children were very young. So, I was raising them. My children were young, I was working, taking care of him [father], and I was also in charge of all of his things. All administrative things and the groceries and payments and other things: my house, plus my children, plus my husband, plus my work. I felt like a crazy person" (Claudia, 220-224).

“The truth is that I had to go to my son’s football match, I had to shop for school supplies, buy food, do everything that relates to household upkeep, plus my mum’s situation because I was the one who had to be checking up on her”
(Margarita, 282-284).

These women articulated how they are culturally expected to successfully serve as carers, wives, and mothers at the same time. The discourse in their interviews reflected the way this expected behaviour is an unspoken norm in Mexico. Their individuality was absorbed by their multiple roles and they were forced to shift priorities and consequently neglected themselves. Each of the participants diverged the reasons why they became primary caregivers. In some cases, they assumed the role because of their marital status, namely, being divorced, widowed, or single. In others, it was that the participant was an eldest or youngest daughter. All cases varied in the circumstances, however, all converged in that once they took the role of caregiver, they felt stuck in their role.

“I am telling you, between my children, my dad, his finances, my house, my husband, and my work. I mean, it was insane” (Claudia, 299-300).

“There was a time when the disease completely overtook me” (Sofia, 189).

“I used to lock myself in the bathroom and cry at night whenever I was alone”
(Margarita, 287-288).

It appeared that these women’s behaviours align with the value of Marianism (described in section 1.2.4). This concept refers to the cultural belief that women should embrace femininity, caregiving, self-sacrifice, and suffering since they mimic the behaviours of a godly woman in the Catholic church, like the Virgin Mary (Cauce & Domenech Rodríguez, 2002). This interpretation might explain why these women felt pressured to comply with society’s expectations. They sacrificed their own wellbeing for the sake of others. However, the need to be many things at once brought a pool of mixed emotions and constant guilt. As a consequence, Claudia, Margarita, and Sofia felt trapped in their roles. It might be possible that they chose not to complain or speak about it since that would be the antithesis of Marianism. In the same vein, Camila resonated with the previous women’s feelings of entrapment. However, her story diverged from the other participants since she was the only one that described how the pressure of her multiple roles had an impact on her health.

“...the doctor tells me ‘no, I think that at this pace you are going to die first because you are the one that is getting worse’” (Camila, 419-420).

To conclude, it was suggested in this subordinate theme that these participants chose to remain quiet because they implicitly felt the need to serve their PwD (influenced by marianism) and to comply with their double care responsibilities. The stress of coping by themselves, accepting the multidimensional roles, and the confusion that comes with it were reasons that these participants attributed to acquiring an AT.

1c. There is no quick fix for caregiving

This subordinate conveys how the participants tried to manage tasks involving caring for a PwD by themselves but eventually realised that there is no easy way to delegate or reduce most activities without help. All of the following participants that tried a ‘quick fix’ mentioned they never considered asking for help from their family members. They explained that they tried to manage the responsibilities by themselves because they feared being rejected by their siblings and/or wanted to prove that they were capable enough to care for their ill parents. Some participants tried to find a way to manage their dual responsibilities in order to regain balance in their lives. However, in time, they realised that dementia is unpredictable and a caregiver cannot expect that a planned schedule or a cognitively stimulating activity will be effective. For example, **Margarita** experienced the frustration of implementing a fixed routine for her mother and realising that this was not feasible. She thought that by imposing a strict routine on her mother, she would be able to predict her mother’s habits and regain some control of her own life. She realised that no matter how much she planned, she would never be able to predict how long her routine would last (since PwDs are unpredictable). Therefore, by trying to plan each day, she felt more burdened. This was assumed because she appeared to be frustrated every time she expressed how her mother was no longer reacting to her usual activities (such as games, calming exercises, and so forth).

Margarita explained:

“...just when you are starting to accept a stage of the disease, the next day you are already in a different one and nothing works” (Margarita, 404-405).

This suggested that the rapid transition from stage to stage made **Margarita** realise that implementing a routine would not be easy. **Margarita** was able to articulate the frustration that emerges the moment a carer realises that all the activities, places, or objects that worked for their PwD one day might not work the next day. In the same vein, **Pablo** felt discouraged realising that he could not control his PwD’s problematic behaviours. He explained:

“...but there is not one single solution... If he reacts in this way or if he becomes restless... do this.... There is no rule, solution, do this, do the other. Nothing! Everything is just a matter of one’s personality, of observing what the person is going to do next. Sometimes there is solution a) – that works, then you re-apply solution a). But it does not work. Then you try b), then c) – you start to make up solutions, we even try to imagine what dad could want. And we try to see if it works” (Pablo, 184-188).

For **Pablo**, being unable to manage the situation became very frustrating as he wanted to find a fix for it. He explained,

“You have to vary each time and think ‘what should I do? How can I make him calm down?’ It’s in the midst of the moment. One has to think fast” (Pablo, 265-266).

Pablo was a natural problem solver and lived a methodical life. Having to care for someone who was unpredictable made him upset and uncomfortable. Not being able to manage the multiple circumstances surpassed his level of tolerance. **Margarita** and **Pablo** experienced the same feeling of frustration trying to manage or to a certain extent control the reactions of the PwD. They also both explained in their interviews that this frustrating feeling motivated them to get an AT since they did not ask for help from their siblings. However, their cases diverged in that **Margarita** was trying to create a routine around her mother, whilst **Pablo** wanted to have a plan in place for whenever his father displayed any of the challenging symptoms of dementia, like aggression.

Sofia thought that hiring a nurse would alleviate her burden and reduce her responsibilities, giving her more control over her life. But in retrospect, it brought more complexities into her life that caused her more stress. As an example, **Sofia** explained:

“It was a big issue when a nurse missed a shift because then you could not leave the house, you could not go to work, you could not do anything anymore” (Sofia, 208-209).

She never thought about the factors surrounding the choice of hiring a nurse. A few of these include the nurse's salary, food or snacks for them to eat, increased energy, gas, and water consumption, her siblings' opinions, the different views of 'how to care', and so forth. **Sofia** realised that "***everything the nurses are spending, plus the quarrels we [siblings] had***" (224) and different "***version[s] of things (407)***" regarding their mother's care were far worse than being the primary caregiver herself. Similarly, after **Margarita** realised that she could not create a routine, she decided to hire nurses. She thought it would be an easy way out of her role since she was expecting to have more time for her husband and children. However, she soon realised that her mother's dementia progressed unexpectedly and her mother's needs could not be covered with just one nurse.

"Then I had to hire two [nurses], then three and in the end, I ended up with double shifts. It was so expensive!" (Margarita, 389-390).

She described her experience with nurses as "***horrible! It is very consuming***" (**Margarita, 404**). **Margarita's** and **Sofia's** experiences revealed that there are no quick fixes or shortcuts for the caring of PwD. Their cases differed in that **Sofia** hired nurses out of desperation because she wanted to have some time for herself. **Margarita**, on the other hand, hired nurses out of necessity since her mother required specialised care that she was not able to provide (for example, feeding through a tube, and so forth). To conclude, this subordinate theme encapsulated the feelings of frustration that caregivers experienced when they were not able to manage or delegate their responsibilities. Notwithstanding this, they chose to remain silent about their frustrations since they thought their siblings would react negatively to their caring decisions. The accumulated frustration and stress experienced by the participants was identified as another contributing factor in their purchase of an AT.

5.3.3 Summary of Superordinate 1: A silent battle

This subsection presented three subordinates to support the superordinate's meaning. The first subordinate was "bearing the burden", which represented the unpleasant experiences the participants went through for the sake of their family. Examples were given of three types of caregiver burden that participants experienced, namely, physical, psychological, and financial burden. The second subordinate was "stuck with the caregiver role". The aim of this theme was to portray the feelings of entrapment that participants experienced when realising that their double care responsibilities (caring for their parents and children at the same time) were overwhelming them. Examples were given about how the participants felt psychologically distressed when they acknowledged the inversion of the parent-child relationship they used to have with their PwD and

the burdensome task of having double care responsibilities. The third subordinate theme was "there is no quick fix for caregiving." This subordinate described the ways some caregivers attempted to find shortcuts to their responsibilities. They tried to find ways to reduce their responsibilities but soon realised that PwDs act unpredictably and unforeseen circumstances occur. In all cases, instead of asking for help from their siblings, they decided to deal with the responsibilities by themselves to avoid judgement, criticism, confrontations, and family divisions. Thus, fighting "a silent battle" (that is, the participant's inner struggles) by themselves made them accumulate negative emotions that eventually motivated them to acquire an AT to alleviate the feelings of burden (as explained in subordinate 1a), entrapment (as explained in subordinate 1b), and frustration (as explained in subordinate 1c). This superordinate also revealed the first finding of this study: the combination of the accumulation of negative feelings and the fear of being misunderstood by people, were the two main factors that motivated them to acquire an AT. This was because the participants from this study wanted to alleviate the negative feelings and stress that their role had without asking for help from anyone. Table 5.3.3 below shows the occurrences that each participant had per subordinate theme.

Subordinate theme	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita
a) Bearing the burden	X	X	X		X		X	X	X
b) Stuck with the caregiver role	X	X	X		X		X		X
c) There is no quick fix for caregiving	X						X	X	X

Table 5.3.3 Summary of Superordinate 1: a silent battle

5.3.4 Superordinate 2: Assimilating the diagnosis

The second superordinate theme, “assimilating the diagnosis”, contains subordinate themes that portray a range of feelings associated with the process of accepting the diagnosis of dementia. All these participants described negative feelings when referring to the condition and conflicting feelings about their experiences as carers. Table 5.3.4a below illustrates the reported occurrences of the participants who found it difficult to accept the diagnosis of dementia.

Superordinate: Assimilating the diagnosis							
Participants	Sofia	Claudia	Maria	Frida	Camila	Valentina	Gloria
Subordinates	Rationalising the diagnosis of dementia	Attitudinal changes	Processing dementia	Emotional reactions after diagnosis, Assimilate the diagnosis	Assimilating the diagnosis of dementia	Changes after the diagnosis of dementia	Making sense of dementia

Table 5.3.4a Summary of subordinates of the superordinate “assimilating the diagnosis”

For this part of the analysis, two main ideas that formed the newly synthesised subordinates were identified:

- 1) The subordinates from Sofia, Claudia, Maria, Valentina, Camila, Frida, and Gloria were grouped together to form “the many meanings behind the condition of dementia”. The conjunction of these participants’ subordinates evolved into this title because it summed up the different negative meanings that participants associated with the condition of dementia. Participants stated that speaking about these meanings was difficult because it required them to open up about their personal feelings that could be perceived by family members as a complaint, weakness, or a way to blame others for their struggles.
- 2) The second set of subordinates belonged to Sofia, Maria, Frida, and Pablo. When clustered together, the elicited interpretation was that participants had “ambivalent feelings” about the experience. These feelings were ambivalent because participants were confused about the different contradicting emotions they were experiencing at the same time. On one hand, they described how difficult it was to live with many challenging situations as a carer and making sense of what dementia was. On the other hand, they expressed how the overall experience of being a carer was good and/or believed that the whole experience was a life lesson. The explored feelings suggested that participants ignored their conflicting feelings to avoid raising any concerns to their family members.

The title of the superordinate theme, “assimilating the diagnosis”, was changed to fit the two general ideas coming out of the subordinates: 1) it was very difficult to speak about what the condition of dementia meant to participants; and 2) they had contradicting feelings about their lived experiences. The new chosen title was “the elephant in the room”. This title encapsulates how the topic of dementia represented something carers did not want to speak about with their family and friends because it was something that uncomfortable and emotionally charged to the caregivers. Table 5.3.4b shows the new titles for each subordinate (represented in rows a and b) and the second superordinate theme from this research is displayed in the top row. Section 5.3.5 will contain the interpretations that were derived from this superordinate theme.

The elephant in the room
a) The many meanings behind the condition of dementia
b) Ambivalent feelings

Table 5.3.4b The second superordinate with its nested subordinate themes.

5.3.5 Convergences and divergences of “The elephant in the room”.

The following superordinate theme, “the elephant in the room” (as described in section 5.3.4), represents how caregivers tried to avoid the emotionally charged subject of dementia. Speaking about dementia made the participants experience a range of negative feelings that were difficult to open up about. Some participants reported that using ATs helped them alleviate the burden of their responsibilities and, therefore, saw the good out of the bad. This subsection contains an introduction of the convergences and divergences from the two subordinates that emerged from this superordinate theme. The allocated titles for the subordinates themes were: 1) the many meanings behind the condition of dementia; and 2) ambivalent feelings.

2a. The many meanings behind the condition of dementia

Participants with occurrences under this subordinate theme ascribed a range of negative emotions to the condition of dementia. To start with, **Camila**, **Frida**, **Gloria**, and **Maria** associated the word dementia with loss and grief.

“There my dad was not my dad anymore. It was like puff! (Makes special sound) After it [dementia] happened we did not know what was happening”. (Maria, 200-201)

“The day that she started with dementia, I lost my best friend. She was the best. The counsellor, the helper, the friend, everything, everything, everything. The confidant. When she started with dementia I lost my best friend (starts crying). As if someone had died, because you talk to her, but she does not care. It does not matter if you talk to her or not. You know what I mean?” (Camila, 406-410).

“...it was the motherly love of always and then not anymore, she was another person” (Gloria, 286-287).

“You are seeing how she is deteriorating because of dementia. How she was a very tall person before, very unreachable... and... and you are seeing her getting smaller. So, you are seeing the physical and mental deterioration” (Frida, 304-307).

For them, dementia represented a silent killer who took away the essence of their loved one. Their quotes were interpreted as grief since they were articulating sadness and expressing the loss of their PwD. These participants associated the condition of dementia with these negative connotations: ‘loss, death, smallness, and deterioration’. Their experiences were emotionally painful. In some cases, they felt as if their parent was no longer alive. They chose to avoid speaking about these feelings because they felt their family would not understand. In contrast, **Sofia** and **Claudia** associated the condition of dementia with a combination of unpleasant feelings such as anxiety and guilt. These feelings triggered their defence mechanisms.

“The truth is that I did not understand what they [doctors] told me. I did not understand what I was about to face, or what was coming. I did not know what the disease was. I think we [siblings] were in denial” (Sofia, 516-519).

Sofia’s statement indicates she was feeling anxious because dementia was something uncertain to her. By denying her mother’s condition, Sofia was trying to protect herself from the painful realisation of what dementia was going to change in her life.

“No, no, I don’t know. The truth is that I don’t even remember. In other words, there are things that I do not remember because it felt like living in a whirlwind. I don’t know what else to say” (Claudia, 264-265).

Claudia repressed all the painful memories from her time as a carer to protect herself. This helped with her mental health as the experience brought an enormous amount of stress and anxiety. Her expression “**living in a whirlwind**” suggested that Claudia perceived her experience as turbulent and unstable.

The subordinate theme “the many meanings behind the condition of dementia” demonstrated how all these participants ascribed negative connotations to the illness. These associations were interpreted as the participants’ personal journey into accepting dementia. Conversely, these participants diverged in the attributed meanings they gave to the condition since all their stories were unique. For example, the feelings of grief and loss were preparing **Camila**, **Frida**, **Gloria**, and **Maria** for the imminent death of their PwD. They were trying to accept that there would be a loss in their lives of an irreplaceable person. In contrast, guilt and anxiety were interpreted as **Claudia** and **Sofia** visualising dementia as their enemy since the condition had brought so much stress to their lives. To conclude, all participants ascribed negative connotations to the condition of dementia because they all had feelings of guilt for feeling constantly burdened and believing that their caring style was accelerating the deterioration of their PwD. Furthermore, a finding of this section was that participants reported that after acquiring an AT, the feelings they ascribed to dementia remained the same (negative). For example **Valentina** and **Maria** shared these negative feelings when reflecting about their experiences even after acquiring the AT

“In fact, it is very sad. I mean, if you’re currently documenting yourself about Alzheimer’s disease, you know it’s known as “the breaker of families.” [only in Spanish speaking countries]” (Valentina, 230-231).

“I did realise how difficult a person with dementia or Alzheimer’s is. I don’t want to experience it again it was bad. We did it because it was our dad, who knows if for a person who was not my dad we would have given all that love and all that patience all the time.” (Maria, 139-141).

However, other participants’ emotions began to stabilise as an effect of adopting an AT that alleviated some of their burden (namely, reduced responsibilities). For example, Frida and Pablo explained how their lives were less burdened after acquiring the ATs:

“Then with the cameras we have been able to monitor how she[mother] is doing, how she is reacting at a certain moment and how the carers take care of her”. (Frida, 117-119).

“It has taken away a weight off my shoulders. From being with him 100%, right now I can easily be less than 50% with him. I can do other things here in the house”. (Pablo, 111-112).

Participants also reported that the ATs were appropriated in ways that helped them avoid many stressful situations. For example, ATs reduced family conflicts (such as by providing video

recordings as factual proof), unnecessary calls (in the case of the emergency button, all were phoned at the same time), and involved all their family members with the responsibility of care (everyone had access to the cameras or needed to respond to the emergency call).

2b. Ambivalent feelings

Participants indicated that they had ambivalent feelings towards various elements related to their experiences as dementia caregivers. These positive and negative feelings conflicted and were accompanied by confusion and insecurities that participants consciously chose not to speak up about.

“Well, at the beginning [of the disease], a lot of sadness with a lot of pain, but then later it was different, like, I accepted it and he showed me tenderness. I mean, I could feel his pain... Oh, that's why he gave me a lot of tenderness. Afterwards, not anymore. It was no longer painful for me, I mean... It was like I accepted it, he was not my dad anymore, he was someone else. My dad was no longer there” (Maria, 445-448).

For **Maria**, the conflicting feelings of sadness versus acceptance and pain versus tenderness were difficult to process. Her contrasting feelings suggested that it took her a long time to accept the disease and to make peace with the conflicting emotions. Since these emotions were complex, Maria avoided speaking about the feelings she was going through. **Frida** described how she had contradictory feelings about her mother.

“I want my mother to die because watching this [erratic behaviour] is worse than feeling that she is gone. I think I expressed myself badly – not that I wanted her to die. But this is worse than having the pain we will experience when she dies” (Frida, 992-993).

Frida is a woman that cared dearly about her mother (see section 4.3.4). However, she felt conflicted by the idea that her mother’s death might bring a sense of relief rather than pain at this stage. She did not share these views with anyone since she felt people would not understand her and label her as a malicious person. The statement demonstrated the contrasting feelings of regret after articulating “**I want my mother to die**” and relief after suggesting that her mother’s death might be a desirable thing for her. Finally, **Sofia** was the only participant that expressed contradicting feelings consistently throughout the interview. For instance, during the first half of her interview, she described the difficulties and struggles of her role.

“There was a time when the disease completely overtook me. I fell into depression twice” (Sofia, 189).

Her views about the caregiving experience at this point were negative. She did not have any extra help or anyone to talk to about her problems. In contrast, in the second half of the interview, she explained how feeling unwell motivated her to acquire an AT because she wanted to decrease her caring activities. It was clear how her views changed when she later reflected on the ways she used and appropriated the technology. She described all the different things that she was able to accomplish and perform with technological help. She went even further into revealing the personal life lessons she had following her caregiver experience.

“However, now I understand that it [dementia] also brought good things because without words, you are teaching your children what true love is. Because you give a lot without receiving anything in return” (Sofia, 257-259).

Despite her view that being an informal caregiver was burdensome, **Sofia’s** words demonstrated her resilience and a consistent transition from negative to positive feelings. All these participants reported that the acquisition of the AT made them see the “good” out of the experience. However, Maria and Frida’s reasons for acquiring an AT differed from Sofia’s. Maria and Frida stated that their decision to buy an AT was triggered by the constant burden of their double care responsibilities, whilst Sofia’s was related to health issues (her feeling unwell). To conclude, the superordinate “ambivalent feelings” presented the ways in which participants experienced conflicting feelings during their role as carers. It was stated that participants made a conscious choice not to speak up about their own feelings to avoid misunderstandings or conflicts with other family members. It was also identified how negative emotions were a contributing factor for buying an AT and that their positive views of the experience were only an effect of using the AT.

5.3.6 Summary of Superordinate 2: The elephant in the room

This subsection presented two subordinate themes, the aim of which was to explain the reasoning behind the superordinate theme, “the elephant in the room”. The first subordinate was “the many meanings behind the condition of dementia” that described the different negative connotations that participants ascribed to dementia. Examples of negative associations were stated as grief, anxiety, and stress by participants. The second subordinate theme was the “ambivalent feelings” participants reported during their caregiving experience. Examples of these were contrasting feelings of sadness versus acceptance and pain versus tenderness. All participants described how they chose to keep the different experienced feelings to themselves for similar reasons as participants from “a silent battle” (section 5.3.3). Their silence can be interpreted as guilt since they expressed a wide variety of emotions that point to feeling conflicted by their actions, decisions, and emotional state. Thus, avoiding “the elephant in the room” (namely, speaking about how dementia made them feel) gave some participants reasons to adopt an AT, whilst for other

participants, it provided a positive perspective of the caregiving experience. In this instance, the AT (such as surveillance and emergency buttons) provided participants with a way to provide care within a reasonable distance and a fair way to involve all their siblings with the caring responsibility (for instance, accessing the video transmission from a mobile phone). These found uses or functionalities helped them to continue avoiding the elephant in the room. Table 5.3.6 below summarises the reported subordinate occurrences by participants in reference to the superordinate theme.

Subordinate theme	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita
a) The many meanings behind the condition of dementia	X	X	X	X	X	X		X	
b) Ambivalent feelings	X		X			X	X		

Table 5.3.6 Summary of Superordinate 2: The elephant in the room

5.3.7 Superordinate 3: Cultural expectations

The superordinate, “cultural expectations”, refers to the traditional elements participants had in common that influenced their experience. The aim of the subordinate themes from this section was to encapsulate the different values and beliefs that were identified from the participants’ accounts. Table 5.3.7a below summarises the occurrences reported by the participants for this superordinate.

Superordinate: Cultural expectations						
Participants	Claudia	Maria	Pablo	Valentina	Gloria	Margarita
Subordinates	Cultural expectations	Instilled cultural roles	Instilled values	Influence of cultural roles	Impact of cultural values	Core values and beliefs

Table 5.3.7a Summary of subordinates of the superordinate “cultural expectations”.

In this case, all subordinates have been allocated very similar titles. Notwithstanding this, it was demonstrated in Chapter 4 that each participant adhered to, practised, and embraced values and beliefs in different ways. Therefore, the title “cultural expectations” did not fully capture the real message that this superordinate was trying to transmit. The three following subordinates represent the general ideas from this superordinate:

- 1) Participants described behaviours that were embedded in them. This means that they embraced and normalised some practices and beliefs because they were brought up with them since childhood. Participants did not find the identified behaviours odd because they are considered normal in their culture. Thus, subordinates from participants who expressed the same behaviours were grouped to form “in one’s blood”. This idiom is generally used when someone’s behaviours or qualities appear to be inherited or innate because they are characteristic of an individual and family (“In one’s blood,” 2015). Since the participants’ parents instilled these behaviours in them and participants have seen the behaviours in their society, they mimicked the behaviours unconsciously.
- 2) The second subordinate described the influence of Catholicism in participants’ lives. Some participants expressed the ways in which spirituality shaped, informed, or guided their behaviours. These participants were gathered to form “a blessing in disguise”. This phrase is generally used to describe how a bad event or unforeseen circumstance turns out to have a positive outcome (“A blessing in disguise,” 2015). In this case, there is an attempt to explain how participants, influenced by their spiritual views, recognised and/or identified positive effects of their challenging experiences.

3) Subordinates from participants that indicated family as their first priority were clustered to form “blood is thicker than water”. This phrase means that obligations to relatives and direct family members were prioritised over any other things (“Blood is thicker than water,” 2015).

After analysing the three main ideas that this superordinate was trying to depict, it seemed appropriate to change the title of the superordinate to “old habits die hard”. This proverb is used to express how some people do not and cannot change their lifelong skills, habits, and behaviours since they are fixed personality traits (“Old habits die hard,” 2015). These set behaviours were a particularity that these participants had in common. All of them appeared to have been set in their own ways. Table 5.3.7b below summarises the new superordinate and subordinates titles. Section 5.3.8 contains the interpretations that derived from this superordinate theme.

Old habits die hard
a) In one's blood
b) A blessing in disguise
c) Blood is thicker than water

Table 5.3.7b The third superordinate with its nested subordinate themes.

5.3.8 Convergences and divergences of “old habits die hard”

The third superordinate theme epitomises the elements that influenced the participants' behaviours during their experience using ATs for their role. The intention of the title 'old habits die hard' (as described in section 5.3.7) is to delineate the traditional elements these participants had in common that directed their experience. Three elements were identified: 1) in one's blood; 2) a blessing in disguise; and 3) blood is thicker than water. The following are descriptions of the convergences and divergences identified from these subordinates.

3a. In one's blood

Each country has a unique set of cultural beliefs. Some countries might be similar to others, but each culture has particular traditions and behaviours that direct the life choices of its inhabitants. In this study, participants expressed two types of embedded beliefs. The first one of these was the division of roles by gender, as indicated in the following quotes:

“My brothers did not get involved at all [in the care]” (Claudia,393).

“When there was a need to participate with money, then it was the time they [brothers] contributed... But we [sisters] always took care of things, we never asked them [brothers] – that’s the truth (laughs)” (Maria, 56-58).

“I already knew that I was going to take care of her. I am the only daughter – I do not have another choice. So, I will do it by myself” (Camila, 399-400).

“My dad used to say, ‘Why do your brothers have to sweep, mop, and clean the kitchen, if there are two women for each brother?’” (Valentina, 541-543).

Claudia, **Maria**, **Valentina**, and **Camila** experienced machismo (see section 1.2.4), which in Mexico is a common behaviour. They all had to assume the role of primary caregivers based on their gender. All the men in each of these participants’ families had the role of financial providers. These participants had been immersed in these views their entire lives to such an extent that they normalised this behaviour. For instance, **Maria** expressed:

“I never thought my brothers did something wrong. We [sisters] always were very clear that we would take care of dad” (Maria, 487-488).

Maria was clearly unperturbed by the gender inequality. All these participants, therefore, categorically accepted this societal and cultural role and unknowingly submitted themselves to an imposed role that, in most of these cases, required the caregiver to be self-sacrificing. The only identified divergence was that **Camila** was the only of these participants that had only one sibling, who was male, and they had a bad relationship. Therefore, based on the participants’ accounts and this identified pattern of machismo, it was assumed that all participants apart from **Camila** perceived machismo more positively because they had sisters that helped them from time to time.

The second belief was to respect and honour their elders. In these stories, the PwD (participants’ parents) played an important role in the participants’ lives. The way many of these participants praised their parents could be interpreted as them perceiving them as figures of wisdom and authority.

“They [parents] made the decision to live next to my place voluntarily. When I got married, I asked my husband that he would grant me my wish of caring for my parents when they were of old age. So I had a deal with him about this”
(Margarita, 363-365).

For **Margarita**, honouring her parents was a priority in her life. She believed that caring for them was a way of showing respect and appreciation. She also believed that this was a great act of love and was a benefit for the upbringing of her children. Furthermore, **Camila** shared the negative views she had of taking an older adult to a nursing home.

“I cannot do it [take mother to nursing home]. My heart does not allow it”
(Camila, 517).

To **Camila**, the idea of taking her mother to a nursing home was unthinkable. Her way of expressing that her “**heart**” (57) would not allow that decision signified that taking her there would bring constant feelings of remorse and guilt. She felt responsible for her health and wanted to care for her until she passed away.

“Nursing homes in Mexico are conditional. They ask you to only bring functional older adults. Basically, they only accept older adults who eat, shower, and use the toilet by themselves. But the rationale of this debate is that if I want to send this person to a nursing home, it is because I, as a caregiver, cannot deal with this anymore” (Margarita, 525-527).

Conversely, **Margarita’s** view was that it was an injustice to condition the acceptance of older adults. She could not find the logic behind the rules of nursing homes. She believed that nursing homes should be for any older adult, regardless of their health condition. This statement explained why Margarita thought poorly of nursing homes. Both participants shared the value of respecting elderly people but they diverged in the way they practised this. **Margarita** believed that living with them is a privilege whilst **Camila** believed that not taking her mother to a nursing home was a way of respecting her. However, both of them believed that nursing homes were inadequate for their PwD needs. It could be concluded that all participants behaved and made caring decisions that aligned with their embedded ideologies. This was the case with all the participants that instinctively knew they were going to be carers and with the ones that believed that sending their parents to a nursing home was not an option (since in their culture this is not well accepted). In this case, participants described how they used ATs to provide their PwD with better care and to protect them from any emergency.

3b. A blessing in disguise

The next subordinate theme refers to the ways in which spirituality shaped, informed or guided the behaviours of some of the participants. In each of these cases, the participants interpreted their higher spiritual force as God. This interpretation ignited something different in all of them. For example, **Sofia** tried to make sense of the caregiving experience through her spirituality.

"I did ask myself why hasn't God called her yet? And what is her mission at this stage? She does not walk anymore; she does not talk. Well, we could think that her life has already been fulfilled and God has given me the grace to understand that she is indeed filled with his glory. For me, she is a little angel who has already won heaven, but if he has not called her, it is because she is teaching me and my siblings how to earn heaven. And every time we go to see her, every time we do something for her, or we stop doing something that we would like to do and you change that to be with her, it helps you climb a step to heaven. So, in reality, she has a mission still, in spite of her state. She has a mission here and God gave it to me and I really enjoy it" (Sofia, 628-637).

For her, saying that God gave her a mission is how she justifies the gradual loss of her mother. Through her rationalisation, she camouflaged the grief inside her that was hidden with the hope that God will notice her efforts and someday reward her. She hid the burdens that came with caring behind her strong faith. When **Sofia** questioned God about his calling, she was really asking when her mother was going to die. She was not afraid of her mother dying as she believed they would be reunited in heaven.

"I used to grab onto a rosary and pray "please, please, please my God". I would never complain "why did you allow this God?" ever! I never had that attitude. I always had it very clear – that it is not God who commands these things, it is bad people who do this. God cannot allow these things, they just happen, but I used to pray to God many times. "My God, if this happens, I ask you please, do not let go, do not let go of me" and it was like that" (Maria, 502-507).

Maria used her spirituality as a shield for her negative emotions. She felt protected by God and thought of him as perfect. To her, prayer brought her the strength and calmness that she needed during her time as a caregiver.

"...[if only] more time would have been granted to us and God our Lord would have allowed us to have her" (Gloria, 794).

Gloria used her spirituality to accept death. She believed God decides the length of time of all lives. She shared the views with **Sofia** that God is perfect and therefore his choice of terminating her mother's life is ultimately his will. This belief helped her grieving after her mother's passing. **Margarita** also shared her spiritual connection with God:

"Speaking of faith, when I was praying at church, I could clearly hear how our Lord said to me: 'That experience was not for you, it was for you to share with others'" (Margarita, 423-425).

To **Margarita**, the voice of God represented how her ego was trying to find a purpose and give meaning to her caregiving experience. As she had spent many years as a carer and she internally felt guilty about dedicating her life in this way, the 'message' became her new purpose. Finally, all these participants converged, in that spirituality was a way to justify, understand, and accept their parents' diagnosis of dementia. Notwithstanding this, they diverged in the reasons for their spirituality. For example, **Sofia** and **Margarita** believed that God gave them purpose by making them caregivers of their parents. **Gloria** used spirituality to accept death and Maria used it to think more positively. It can be concluded that participants used their spirituality as a coping mechanism.

3c. Blood is thicker than water

Several participants expressed that family was their highest priority in life. All these participants communicated the love, support, closeness, and respect they felt for their respective PwD. All described that this value contributed to the decision to become their parents' primary caregivers. However, two different intentions behind their devoted familism were identified. The first motive was the feeling of love towards their parents.

"Well, I believe in loyalty. Being loyal to him after he took care of us. He always gave me everything – he was a good father. So for me, it was a way to repay him with the same favour. Like a kind of love, out of loyalty to him" (Claudia, 406-408).

"Look... I never did it [caring for my dad] out of obligation, it was something I did with a lot of love. I would do it again, maybe some things differently" (Maria, 478-479).

Claudia's comparison of love to loyalty was an expression of how she perceived love as a provision. To her, being next to her dad and serving him was a way of loving him. She also felt that reciprocating the 'favour' of caring was an act of true love. In the same vein, **Maria's** choice for care was a way of professing love through actions. Her statement declaring that she was not doing this out of obligation is a way in which she expressed her sense of familism. She was communicating her feeling that family comes first. The next reason for their sense of familism were feelings of completion and realisation.

"It gives you satisfaction to be able to help her [mother]. My mum gave me everything. She gave me her entire life. She was my best friend" (Camila, 405-406).

"When you are young, parents give you everything. Now that they are old and cannot do all their activities, it is our turn to give back to them" (Pablo, 238-239).

"I was the youngest of six siblings, so I see the experience of caring [for parents] as a way to thank them for all the sacrifices they made for me at some point. It brought me joy" (Margarita, 462-464).

Camila and **Pablo** felt the need to give back to their ill parents. Both of them saw their caring roles as their life duty. They both thought that being self-sacrificial whilst serving as a carer was acting how their respective parents raised them to be: loyal to their families. **Margarita** saw her caring role as a form of gratitude. To her, positive feelings flowed when she spent time with her family and honoured her parents. She described joy and a sense of satisfaction because she felt that she did not owe her parents anymore for all the sacrifices they had made. These last three participants felt compelled to serve their parents as a way to fulfil their need to feel that they had completed their mission (to care) and realisation (acted as a good son/daughter). It is clear that all these participants prioritised their PwD because they were family members. However, these cases diverged in why they assumed the role of caregivers. On the one hand, **Claudia** and **Maria** justified their role out of love and respect for their PwD. On the other hand, **Camila**, **Pablo**, and **Margarita** became caregivers because they felt it was their duty and it was a way to thank their PwD for all the provisions they received throughout their childhood.

5.3.9 Summary of Superordinate 3: Old habits die hard.

This subsection introduced the three main elements that aimed to justify the reasoning behind the superordinate title, “old habits die hard”. It was stated that this phrase referred to the embedded ideologies, habits, and behaviours that various participants adhered to and found hard to change, and that influenced the way they used, chose, and thought about ATs. The first explored subordinate was “in one’s blood”, which described some cultural values that have been normalised and behaviours that have been part of the participants’ lives for as long as they could remember. Examples of these values were stated as traditional gender roles (for example, women are carers and men are providers) and respecting the elderly by participants. The second subordinate was “a blessing in disguise”. This phrase was used to explain the impact of spirituality and how it directed the participants’ views in life and how it acted as a coping mechanism. The example given was about participant who believed that God gave her mother dementia as a way to teach her entire family a life lesson. The final subordinate, “blood is thicker than water”, explored the importance of the bond participants had with their family members. The distinct value of familism and how it affected the participants’ caregiver role was given as an example. Table 5.3.9 below provides a summary of the explored subordinates and occurrences they had with each participant.

Subordinate theme	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita
a) In one’s blood		X	X	X	X	X	X	X	X
b) A blessing in disguise	X		X					X	X
c) Blood is thicker than water		X	X	X	X		X		X

Table 5.3.9 Summary of Superordinate 3: Old habits die hard

5.3.10 Superordinate 4: Appropriating the technology

Through its subordinate themes, this superordinate theme captured the different ways in which participants' ATs were appropriated. Table 5.3.10a below exhibits the different instances that describe the ways participants appropriated their ATs for their caring role.

Superordinate: Appropriating the technology						
Participants	Sofia	Maria	Frida	Pablo	Valentina	Margarita
Subordinates	AT served as a source of accountability	Appropriating technologies	Technology served as an assistant	Technology as an enabler of care	Appropriate technology pragmatically	Benefit of appropriating the ATs

Table 5.3.10a Summary of subordinates of the superordinate “appropriating the technology”.

The original title for the superordinate, “appropriating the technologies”, synthesised the action that all these participants were doing (that is, to appropriate the piece of technology). However, the main idea was still not clear. Two subordinates were derived from the occurrences to refine the lived experiences of these participants with ATs.

- 1) This subordinate encapsulates the idea of how ATs made participants' caregiving roles easier and changed their caregiver experiences. Participants who embraced and accepted the technology were grouped to form “seeing the good in ATs”.
- 2) Participants showed how they used the technology to fit their own needs. For example, if their AT was a surveillance camera, participants explained the creative ways in which they used the camera for something different to the original purpose to fit their changing needs. The participants' subordinates that resonated with this idea were grouped together to form “necessity is the mother of creativity”. This phrase signifies that people in difficult or desperate times tend to improvise new ways to do things and/or fulfil their needs with the resources available (“Necessity is the mother of innovation,” 2015).

In order to describe the idea that the participants' experiences were conveying, the superordinate's title was changed to “a change of heart about the AT”. Participants under this superordinate theme were going through the process of accepting the technology. Once they saw the benefits it brought into their lives and the way it changed their outlook of the caregiving experience, they changed their opinions about the AT. The phrase “change of heart” is used to express when someone changes their mind and/or feelings about a specific subject (“Change of heart,” 2015). Table 5.3.10b below summarises the assigned descriptors to the superordinate with its nested subordinates. Section 5.3.11 contains the interpretations that derived from this superordinate theme.

A change of heart about the AT
a) Seeing the good in ATs
b) Necessity is the mother of invention

Table 5.3.10b The fourth superordinate with its nested subordinate themes.

5.3.11 Convergences and divergences of “A change of heart about the ATs”

This last superordinate theme captured how ATs influenced the carers and their experience in multiple ways. The title, “a change of heart about the ATs” (as described in section 5.3.10), referred to how the participants accepted the ATs into their lives after testing the ATs’ efficiency for their role. Two subordinates were identified: 1) seeing the good in ATs; and 2) necessity is the mother of invention.

4a. Seeing the good in ATs

In this subordinate theme, participants detailed the ways they believed that ATs affected their lives. These results revealed two ways in which carers believed they were benefiting their lives by using an AT for their role. The first identified modification was that carers’ independence increased significantly. Their constant physical presence was no longer required as they had a reliable way of monitoring their PwD.

“I no longer need to be 100% next to him [father]. I can walk around doing other things here in the house. Because before, without the camera, I had to be here. If I had to do other things I could not move” (Pablo, 93-94, 96-97).

“I had to shower late at night until I was able to leave her asleep. Sometimes I showered at twelve o'clock at night. Then, with the little camera, all my problems were solved” (Camila, 155-157).

“In a certain way, if you cannot be next to the sick person all the time, it gives you a certain tranquillity to see what they are doing. I believe that technology is a good tool that allows you to be able to continue with your life” (Sofia, 130-132).

For these three participants, the inconvenience of having to be by their parent's side took away part of their individuality and free time. **Pablo** felt increasingly frustrated at not being able to continue his job and to leave home for work without feeling guilty. Using an AT changed this, and these feelings gave him a sense of freedom. Since becoming a carer for her mother, **Camila's** daily routine became unpredictable, making her exhausted and constantly irritated. Her statement, “**all my problems are solved**” (157), signified the sense of relief she felt and symbolic trust she placed in the device. The statement also revealed **Camila's** need to control, as she felt troubled when she could not carry out her regular activities. In contrast, **Sofia's** expressions of “**tranquillity**” (131) and “**able to continue with your life**” (132) manifested her hidden depression and longing for a change. It was difficult for her to trust the AT completely but, given all the different factors around her case, this newfound ‘freedom’ gave her hope. In a similar vein, **Frida** described how her mother's aggressive stage was her biggest concern.

“And then the stage of aggressiveness began. Whenever it happened, they [nurses] phoned me saying ‘Mrs, your mother is very aggressive’. And then, while on the phone with my mum, I tried to calm her down by saying ‘Mummy, calm down. Look, go to the room. Mum...’ I was checking her in real-time through the camera, to see how she was responding to my call” (Frida, 76-80).

She explained that sometimes her mother's aggressive behaviour was triggered by just being in the same room with her. It got so severe and frequent that she had to hire nurses to help her. She opted for using a wireless camera to observe and her mobile to call the nurses. **Frida** then simultaneously helped them through the episodes of aggression. This simple yet effective solution fulfilled her needs. This utilisation of these devices as assistive technologies gave her a sense of bilocation (that is, being in two places simultaneously). This made her feel guilt-free and reassured her that her mother was safe. Similarly, **Margarita** described optimistic feelings towards ATs and the way it transformed her life.

“Of course, I started to be calmer as I knew that if there was an emergency they would find me and if I was not available then my siblings could help. So, it brought a lot of peace to me and my husband” (Margarita, 51-53).

The disclosed feelings of “**peace**” (53) and “**calmness**” (51) represented the trust she placed in the technology. She was able to finally and justifiably rest in the assurance that she was no longer the primary caregiver. To her, this was an impactful moment, because the technology not only gave her some independence but it also made all of her siblings accountable for their mother's care. The next adjustment that ATs brought to these participants' caring role was the beginning of a new routine.

"I wake up in the morning, grab the phone to see if there are any messages, and then I check the cameras. Then at midday, you see if she sat down to eat or if any of my sisters are going to go. Then in the evening, for example, since we are no longer there, the nurses stay with her [mother]. So like I said, you enter [the cameras/videos] to see that everything is fine, if she is asleep, etc..." (Frida, 432-437).

To **Frida**, her role took on a completely new meaning as she was now in control. She was able not only to see her mother whenever she wanted, but she was also able to decide what to do in her day-to-day life. **Frida** represented the acquisition of the AT as regaining her life back after struggling for years with her role. In contrast, **Camila** also described her new routine:

"How can I explain this to you? If I was downstairs, seeing that she was already awake, then I will see how her day was unfolding. And then, if I go out or something, I'm seeing her too. And even if I go on a trip, I'm seeing her and watching her" (Camila, 99-101).

However, she was not as methodical and fortunate as **Frida**; she did not have any extra help (namely, nurses) at home, so the burden of her old routine was alleviated to some extent but it was not completely improved. She was able to have a newly acquired sense of independence but she still needed to feed, bathe, groom her mother, and so forth. All these participants saw the good in ATs after the technology provided a benefit to their lives. However, they differed in the reasons that they benefited. Some participants mentioned the convenience of monitoring through their mobile phone, assisting nurses from a distance, having a new routine, and so forth.

4b. Necessity is the mother of invention

The following participants disclosed the different ways in which using an AT during their caring role modified their personal views of the lived experience. Several caregivers pinpointed that using ATs facilitated two particular actions that transformed their caring experience. The first was that ATs allowed them to document the experience in various ways. All the following participants documented what they needed to provide better care with the help of an AT. However, all stored videos had a different purpose and meaning to each participant. For example, **Valentina** explained how she used the AT as the channel between her mother and medical appointments.

"When I took her to her medical appointments, we first took her down in a chair and then in the wheelchair. And then she didn't want to walk anymore. So we took videos with my phone and took them to the doctor. This is how I received her medicines. With the evidence of video and photographs" (Valentina, 117-121).

To **Valentina**, the AT was much more than just a monitoring instrument. It was, to a certain extent, a way to facilitate health services and appropriate care for her ill mother. With the evidence that she documented, she was able to receive her mother's prescriptions that were prescribed to manage the dementia symptoms. Moreover, **Claudia** and **Pablo** narrated how with their AT they were able to identify elderly abuse.

"I realised by chance. My brother came to visit us and we started talking, he asked, "how is dad?" I responded, "well". I told him I had not been in the house, and I had not known about him for three days. And I suggested we should watch the recorded videos from the camera to see the nurses work and we discovered abuse. We fired the responsible nurse, but we did not tell her the reason. We just told her, "we no longer need your services" and that was it" (Pablo, 221-224).

"Well, thanks to that technology, I realised that a nurse was mistreating him" (**Claudia**, 92-93).

In both abuse cases, the nurses were captured on video with a monitoring camera that assisted **Claudia** and **Pablo** with proof of these events. For **Claudia**, she expressed gratitude regarding the AT as this signified her father's security to her. Similarly, for **Pablo**, being able to capture this event was beneficial since he was able to go back in time and assess this risk immediately. Another form of documentation was shared by **Valentina** who, in contrast to the other two participants, was trying to document proof of her innocence. She explained:

"It was mainly to record us – those who took care of her [mother] and to put a stop at a given time if a situation happened. For example, when mum started to deteriorate more from her dementia, she bit me and didn't let go of my finger. I had to slap her with my other hand to open her mouth because she was already cutting my finger. So, things of that nature to have evidence that there was no abuse" (Valentina, 41-43, 48-50).

Valentina was afraid that her actions could otherwise be interpreted in the wrong way by her siblings. She felt outnumbered and decided to protect herself with an AT. What this device meant to her was truthfulness and transparency because it gave her valid proof against any wrongful claims. Furthermore, **Valentina** also clearly described the final form of documentation. She used her devices to capture mementoes of her mother.

“...images of my mum still being my mum. She, talking with my siblings, with us, with her grandchildren, watching television because she really liked it. The most positive thing was that they were left for posterity” (Valentina, 162-166).

Her hopelessness increased alongside her mother's deterioration. She felt desperate to freeze her mother's few lucid moments. She expressed how she felt heartbroken that her daughter would never meet the real essence of her grandmother. This form of testimony represented her grief as it helped her to mourn.

The next identified action was ubiquitous caring. This refers to the feeling that ATs give caregivers of being able to be everywhere. In other words, ATs provide a sense of omnipresence to carers by allowing their constant monitoring of the PwD from anywhere as long as they have an internet connection. In **Camila's** words:

“...I can monitor my mother all the time 24 hours a day and not be next to her 24 hours a day. It gives me peace of mind because even though I'm in my bed, I can watch her from there” (622-624).

The first identified use of ubiquitous caring was to provide objectivity during the caregiving experience. Family members often had arguments and different opinions about the standard of the care and how it should be provided. Engaging in the game of 'he said-she said' was a common theme among these participants. **Sofia** helped to exemplify this point.

“The need to observe the care of my mother was covered and that relaxed the attention of my siblings over me. Because before, they knew about mum through what I said or through what the girls [nurses] said and that was a big problem for them. The girls had a version of things and I sometimes had another, which we discussed with the rest of the family and sometimes things were different. So I think the cameras brought the real truth of what was really happening” (350-355).

For **Sofia**, ATs brought peace to her lived experience. She felt protected by this technology because she was no longer going to be wrongfully accused by her siblings. She confessed that the origin of her health problem was rooted in her family issues. Therefore, she saw this technology as a figurative medicine that restored her mind (that is, her sense of peace) and body (namely, by reducing stress). **Pablo** also felt that his experience was changed by the objectivity that the AT facilitated.

“The main reason is for my own peace of mind. It is not to be monitoring people [nurses]. But when there is a situation (namely, accident)... When we suspect that something is not right. Then, we go and look at the camera. With that, we can see what happened or didn’t happen when he [father] was alone” (Pablo, 215-219).

Notwithstanding this, the difference between him and **Sofia** was that his aim was to use this power of surveillance to exclusively check on his father. When an unfortunate incident occurred, he used the AT to objectively understand how his father got injured and helped him by learning the truth.

The second use of ubiquitous caring was the capacity for 24/7 surveillance. **Maria’s** and **Claudia’s** objective was the same – to monitor the nurses as they both distrusted them.

“Look, instead of using it to check my dad, it was to check the nurses. To see if they were doing their job” (Maria, 4-5).

“...Well, it was more to see how the situation was, if the nurse was standing, sitting, was with him, was changing him, or moving him into a new position. As he was in bed, you had to be rotating him so that he didn’t get any bed sores. Then, I would get in [computer] to see if they had already changed their position, or if the caregiver was asleep, or if she was awake, or what was basically happening” (Claudia, 20-25).

For **Maria**, the job of a nurse meant to be next to the patient, assisting him at all times. As her expectations were high, she used the AT to monitor and bring up to the nurses what she saw as flaws. **Maria** thought it was unacceptable to read a book or make a call during working hours; therefore, she sought to make the nurse's job difficult for them. In the same vein, **Claudia** wanted her nurses to work at all times. Nevertheless, they differed in that **Claudia** did find it acceptable to allow the nurses to have breaks as long as her father was cared for properly. These two participants exemplify the way the action was the same (namely, to monitor nurses), but the intentions were quite different.

5.3.12 Summary of Superordinate 4: A change of heart about the ATs

This subsection described two subordinate themes that demonstrated how the main ideas of these themes were suitable for the superordinate's title "a change of heart about the ATs". The first subordinate was "seeing the good in ATs" that described how participants embraced the benefits that the ATs brought to the caregivers' role. Examples of these benefits were increased carers' independence and a new functional routine. The second subordinate was "necessity is the mother of invention", which referred to the different ways the caregivers appropriated the ATs in a unique way to fit their needs. Examples of the uses of ATs were stated as a tool for documentation and a tool that provided a sense of ubiquity. Thus, the pragmatic uses participants found for their ATs and the participants' recognition of the multiple benefits the AT had on their role made them have "a change of heart about the ATs". Some findings from this superordinate were that participants embraced the AT after they tested it and it gave them positive results and participants appropriated the AT to suit their own needs, not the needs of the PwD. Table 5.3.12 below exhibits the occurrences each participant reported for the corresponding subordinate themes.

Subordinate theme	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita
a) Seeing the good in ATs	X	X	X	X		X	X		X
b) Necessity is the mother of invention	X	X	X	X	X	X	X		X

Table 5.3.12 Summary of Superordinate 4: A change of heart about the ATs

5.4 Summary of findings

The section contains the different findings from this study. The findings are only applicable to the participants from this study. As the chapter has shown, four main superordinate themes came out of the group analysis. Each of these themes, presented in Table 5.4 below, represent the identified patterns from the lived experiences of Mexican ICs of PwDs who used an AT for their role.

Superordinate theme	Findings	Reference from Chapter 5
A silent battle	The participants from this study wanted to alleviate the negative feelings and stress that their role had without asking for help from anyone. Therefore, the combination of the accumulation of negative feelings and the fear of being misunderstood by people, were the two main factors that motivated them to acquire an AT.	Section 5.3.3
The elephant in the room	The participants avoided speaking about how dementia made them feel. Some participants stated that the accumulation of stress gave them reasons to adopt an AT. Whilst other participants reported the AT influenced their perspective to see things in a positive way about their caregiving experience.	Section 5.3.6
Old habits die hard	Participants values and beliefs played an important role in their overall decision of whether they should adopt an AT or not. If the AT did not represent a threat or opposition to their values, then IC decided to test the technology.	Section 5.3.9
A change of heart about ATs	ATs directly influenced the IC role and caregiver experience. This was revealed when the IC reported a change in the degree of responsibilities they had and in the ways they appropriated the ATs to fit their own needs.	Section 5.3.12

Table 5.4. Summary of findings

5.5 Reflexivity Statement

Carrying out the group analysis was the most difficult part of this investigation. At the end of the idiographic analysis, I realised that I had an overwhelming amount of data. I remember having to make an internal system to organise all the data before I started the analysis. With the help of binders, folders, and highlighters, I started my journey. I decided to work with printed material because I have a photographic memory and it made it easier for me to make sense of all of my results. In a strange way, it made me feel more immersed in my data and it felt more realistic than having everything on my computer. I would like to state that the group analysis consisted of many detailed steps and procedures (such as introspection) that, for me, were clear and straightforward. However, I found that for my supervisors and sometimes my audience (such as in seminars), it was difficult to follow. This was a big learning curve for me since I was able to see this flaw within my work. After my realisation, I addressed all the sections that were not detailed enough. I started documenting and explaining each step more thoroughly and I incorporated visual aids. During my auditing sessions with one of my supervisors, I was able to refine my interpretations and achieve a detailed level of transparency in my work. I also had the opportunity to discuss my work in three different research groups, conferences, and seminars, in which I received very valuable feedback. Refining my themes and interpretations was the most time-consuming part of my whole investigation. Notwithstanding this, I was able to see the benefits it brought to my thesis.

Another challenge was encountered during the writing process of the group analysis. I had to cautiously revise and reflect on their idiographic accounts many times to make sense of their experiences. As I was writing, I found new things each time that needed my attention. For instance, some of the first interpretations were very different from the final interpretations. Specifically, when I was analysing their similarities and differences, I came up against an obstacle. It was difficult for me to discard themes since I thought that every code was important. I feared that my interpretations were going to lack depth and, therefore, appear weak. It was a challenging process to learn to hear the themes speak to me and to question whether a code would make a difference in my analysis. I learned slowly and cautiously how to interpret the participants' lived experiences. Re-reading my reflexive diaries were of much help because I captured the raw emotions and opinions I had during the day of the ICs' interviews. I found it also useful to replay the interviews in my head whilst hearing the audio recording the day of the interview. In retrospect, I feel like every time I went back to those diaries. I found my preconceptions, as uninformed opinions, were based on popular culture. I think that identifying this flaw made me grow as a novice researcher.

The process of selecting the final titles for my superordinates and subordinates was also a very challenging process. I decided to use metaphors, idioms, and sayings to encapsulate the emerging themes. I got this idea from reading my participants' transcripts endless times and realising that they used, very frequently, hyperbolic language (namely, they exaggerated their experiences and opinions). Using this approach made me feel like I was doing their narratives justice since it was a way to honour their experiences in an authentic way. Finding a balance between being respectful and accurate with those titles was challenging because dementia caregiving is a vulnerable subject to portray.

5.6 Conclusion

Chapter 5 contained the results and rationale for the group analysis. It also synthesised the findings from this phenomenological study. Over the last two chapters, the researcher has made clear the process in which the results were obtained and demonstrated the rationale behind her interpretations. This chapter concluded the section of this thesis that pertained to the analysis and presented the main findings from this study. Section 5.2 provided a comprehensive description of the steps followed for the group analysis. Section 5.3 presented the results of the group analysis. A total of four superordinate themes and ten subordinate themes were reported for the results. The final superordinate themes were: (1) a silent battle, (2) the elephant in the room, (3) old habits die hard and (4) a change of heart about ATs. Section 5.4 synthesised the findings of this research and section 5.5 provided the researcher's reflexivity statement for this chapter. The next chapter (Chapter 6: Discussion) aims to answer the research question and provide a discussion about the results from this chapter.

Chapter 6: Discussion

6.1 Introduction

As explained in Chapter 1 (section 1.5), the aim of this project was to explore the lived experiences of Mexican informal caregivers (ICs) of a person with dementia (PwD) with assistive technologies (ATs) used for their caring role. Chapter 3 described the Methodology for this study, in which nine ICs of PwD were interviewed using a semi-structured approach in Mexico. The data were analysed in two parts following Interpretative Phenomenological Analysis (IPA). The first set of findings belonged to the idiographic analysis that allowed an in-depth exploration of the participants' thoughts and feelings around the AT, these are described in Chapter 4. The second set of findings emerged from the group analysis; these reflect generalisations that only apply for this group of people and these are presented in Chapter 5. Four major superordinate themes emerged from the group analysis:

1. A silent battle;
2. The elephant in the room;
3. Old habits die hard;
4. A change of heart about ATs.

In these themes, the wide range of lived experiences of participants during their role as dementia caregivers using ATs was synthesised. However, it was difficult to select one theoretical framework for this study's discussion since the results were extensive and involved many complex feelings. Instead, this chapter has three specific aims: 1) to introduce the contextual particularities that influenced participants' sense-making during their caregiving experience with ATs; 2) to provide a synthesis of the contributions of this research which will be illustrated through a diagram; and 3) to discuss the key findings of the thesis within the context of the relevant literature in relation to the research question that was originally set out in Chapter 1 (section 1.4):

How do Mexican informal caregivers of people with dementia make sense and experience their use of assistive technologies to aid their role?

The participants in this study spoke about the different challenges they experienced as part of their caregiving role. The participants' experiences were divided into two parts: pre-adoption of AT and the adoption phase. Before the adoption of ATs, participants attributed a combination of different negative feelings (such as caregiver burden and feeling trapped in the role) and double care responsibilities as the factors that motivated them to acquire an AT and care for their own wellbeing. It was revealed in section 5.3.4, that the participants, as a defence mechanism, had negative connotations of the condition of dementia. It has been highlighted by the findings that participants acquired ATs after they were able to process the diagnosis of dementia and realised that they needed help. During the adoption phase, participants first tested the AT (the findings indicated that the ICs in this study were cautious technology adopters). Finally, once ICs found

ATs to be beneficial and easy to use, they fully accepted them and appropriated them to fit their own needs.

The chapter is divided into six main sections, which are outlined as follows. 6.2 The Mexican informal caregiver worldview – that contains an in-depth and critical discussion of the historical, social, and political factors that formed the participants' worldview. 6.3 The Mexican informal caregiver experience with ATs – the aim of which was to discuss the findings that were revealed through their individual interviews. In this section, a sequence of stages is presented with the identified patterns from the group analysis using a diagram to aid the discussion. 6.4 The role of ATs in mediating the experience – in which the researcher explores how the ATs acted as mediators during the last stage of the experience using concepts from postphenomenology. 6.5 Conclusions – which contains a summary of the discussion.

6.2 Mexican informal caregivers sense-making of the experience

The aim of this section is to describe the identified contextual particularities that influenced participants' sense-making during their caregiving experience with ATs. Fox et al. (1999) suggested that studies of ethnic groups and dementia caregivers should not only focus on the values and traditions of a culture, but also concluded that macro-structural factors (that is, the historical context), alongside values and beliefs, could provide a more comprehensive worldview of informal caregivers. The purpose of the discussion is to inform the reader of the different factors that shaped the mindset of the Mexican ICs regarding their lived experiences. It also aims to draw a holistic picture of the participants' past or upbringing and present (that is, the time of the interview) from their narratives. In other words, to provide the reader with key elements from Mexico, including influential events and empirical evidence that shaped their worldviews and sense-making. These formed views informed the way they used and thought about technologies. Uncovering the participants' unique perspective was achieved by following a double hermeneutics approach (described in section 4.2.4) that allowed the researcher to understand participants' sense-making (Smith & Osborn, 2003). In line with the guidance from the hermeneutical circle, the elements that were considered for this contextual analysis were historical, social, and political underpinnings (Gadamer, 1976). The elements emerged from the ICs' interviews and demographic data. These were later analysed against the existing literature. These details provided the essential features so that the participants' views of the world could be interpreted (Lopez & Willis, 2004). The aim of all the following descriptions is to provide a thick description of the participants' worldviews. In this research, thick description refers to providing the context of a particular experience, informing the meanings and potential motives of the stakeholders involved, and explicating how past events influenced stakeholders' actions and behaviours (Denzin, 2001). Some participants' quotes have been used at times to aid the interpretations of findings.

History. It is important to learn about the historical context of Mexico to understand some of the underpinning behaviours from the participants. Two main components of Mexico's history were identified as factors that shaped the participants' views about the world; namely, *the emergence of television in Mexico* and *the Tlatelolco Massacre* (as described in section 1.2.5). It must be borne in mind that, whilst differences existed within all the participants in this study regarding their very specific situations, in the broader picture of their experience, all shared generational events influenced their upbringing. Generational events should be taken into account since they are the collective image of historical, social, political, and global elements that influence a generational group's lives (Soto et al., 2018). In this study, participants were between 49 and 64 years of age at the time of the interview. This places them in the category of the people born between 1946 and 1965 – referred to as the *baby boomer generation* (Bonvalet et al., 2014). Baby boomers had the opportunity to watch on television (which at the time was an emerging technology), events that transformed the world, such as the moon landing, the fall of the Berlin Wall, the assassinations of President John F. Kennedy and Martin Luther King, and other influential events that shaped the world (Fay, 1993). Therefore, it is fair to assume that television acted as an informer of the external world. Television was first commercialised in Mexico around 1948, however, only the wealthiest were able to afford it at that time (Ruiz, 1991). Around the 1960s is when, in Mexico, having a television was affordable and ever since, this technology has had an immense impact on the country's politics, economy, and culture (Bustamante, 2013).

Furthermore, baby boomers were amongst the first generation to include television as part of their daily routine with their families (Fay, 1993). For instance, traditionally, many Mexican families watched the broadcasting news segment together before dinner during the early 1960s (Renero, 1992). This context is an indicator of the way in which Mexican baby boomers (the ICs in this study) normalised, socialised, and integrated technology into their daily lives. Therefore, it can be argued that from an early age, the participants in this study accepted the idea of having and using technology at home. This can be reflected in several participants' accounts when asked about their level of confidence and comfort around technologies. For a specific example please see section 4.3.6 Pablo's account where she describes feeling very comfortable using his AT.

"OK, comfortable ... I understand it[technology]. Not 100%, but I'm updated." (Pablo, 71-73)

Moreover, Darley (2002) suggested that baby boomers formed their opinions about technology based on what TV shows dramatised about them. In the same vein, Robins (2002), argued that people from this generation have false ideas about technology given that TV sold them the idea of futuristic artefacts that were based on science fiction shows (TV programs). The previous statement resonated with participants' expectations about future home technologies. For example:

"[I would like] A robot that could entertain her [person with dementia], that could tell her stories... with a human face or very handsome. Because no, not ugly, not an animal, but a pretty face, whether it's a boy or something, like, not too big" (Gloria, 848, 860-861).

Some participants from this study expressed wanting pieces of technology that mimicked those from science fiction shows. Therefore, it can be concluded that television did inform and help form their ideas about technologies. Bustamante (2013) suggested that between 1952 and 1970, Mexico suffered many societal changes as a consequence of the expansion of television. She argued that Mexico's government manipulated the media with politically charged messages and transmissions that favoured a specific political party and influenced the minds of Mexicans. Therefore, Mexicans witnessed, through newspapers, radio and television, national events that changed and affected their views of the world.

Politics. Mexico's political climate is complex. Randall (2006) suggested that this complexity derives from the three different elements that define Mexican political values: the nationalist, revolutionary, and Catholic identities (please refer to section 1.2.5 for description of these three views). The participants in this research were born between 1946 and 1965. This means that they might have been influenced by the political views of PRI since they were in power throughout participants' childhood, teenage years, and early adulthood. It was noted in section 5.3.8 that the majority of these participants actively practised and were influenced by Catholicism. The Catholic Church at the time had the power to implement governmental decisions, could speak about their political views at liturgical services, and actively participate in public debates (Loaeza, 2013). During this period, Mexicans saw much injustice, corruption, and violence, which changed the citizens' mentality about their government (Morris, 2009).

Society. Social and technological progress are two concepts that are seen to be instrumental in the advancement, change, and emergence of societies (López Peláez & Kyriakou, 2008). With this in mind, it was assumed that since social influences are constantly changing, so are the meanings, usages, and appropriations people have for technology. Technological advancements commonly challenge societal boundaries, for example, social media has changed the way people communicate on a global scale (Haddow & Haddow, 2013), the internet has changed voting in certain countries (Mohen & Glidden, 2001) and smartphones have led to real-time notifications for news and viral videos (Warren et al., 2014). Therefore, Licoppe & Smoreda (2005) suggested it was imperative to consider relevant social influences behind the phenomenon under investigation.

Furthermore, Mackay & Gillespie (1992) suggested that a person's social class, gender, demographics, and generational context are key societal influences to comprehend the meaning people give to domestic technologies (such as ATs) and inform designers and developers of what people prefer in technologies.

According to Dicke et al., (2019), traditional gender roles are directly influenced by a country's cultural values. The findings from this study indicated that female participants unknowingly echoed some of the underpinned behaviours of mariismo. The female participants did not see being carers as wrong and they accepted the role willingly. Their reactions and behaviours can be explained by the way the traits of mariism are highly regarded in Mexican culture and society.

6.3 The Mexican informal caregiver experience with ATs

In this section, there is a discussion of the findings that were derived from the individual and group analysis within the context of the existing literature. The detailed results from the analysis revealed that all participants, to a certain extent, went through five stages during their lived experiences as caregivers. The aim of these sequential steps is to synthesise the participants' lived experiences as dementia ICs. The diagram (figure 6.3) below exhibits the steps. These are: 1) emotional triggers; 2) avoidance; 3) personal values assessment; 4) self-forgiveness; and 5) acceptance. Through all steps, the feelings and emotions of the participants are revealed and discussed. However, step 4 is the stage where the idea of AT as a solution emerged and step 5 is an explanation of how the acceptance of the technology occurred during the experience. Therefore, in section 6.4, an exploration of the technological side of step 5 has been developed using concepts from postphenomenology. The aim of the technological exploration was to exemplify how ATs mediated the caregiver experience and transformed the caregiver role. The present diagram is not cyclical and the findings from the study did not hint at any specific time frames for the stages. The order in this diagram is important since it is an authentic representation of how the participants experienced the progression of these phases. In the following subsections, there is an exploration and discussion of each of the steps from the model in light of the wider literature.

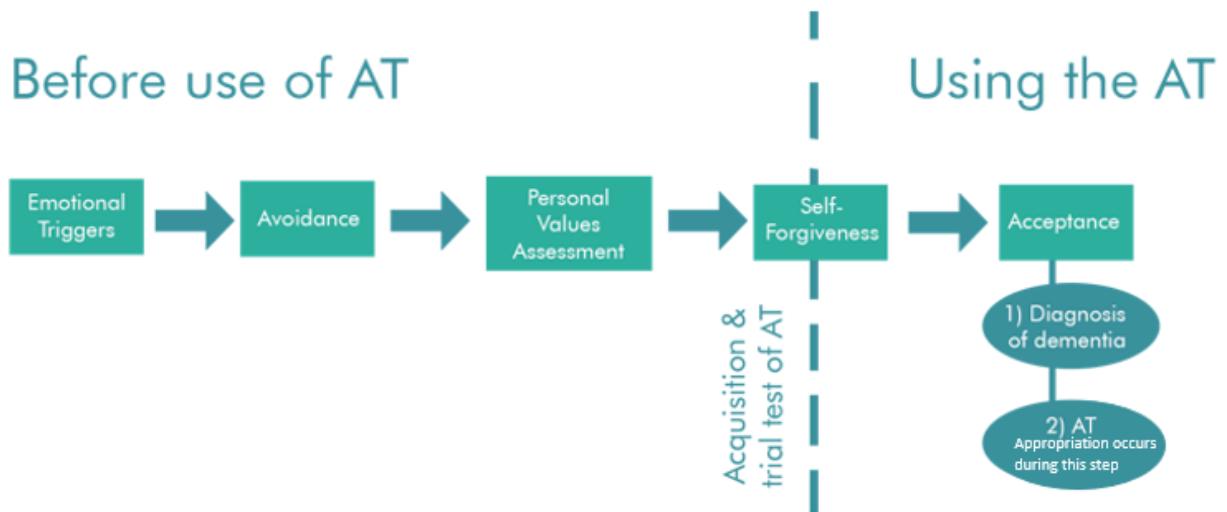


Figure 6.3. The Mexican informal caregiver experience with ATs

6.3.1 Step 1: Emotional triggers

The first step of this model was derived from the first superordinate “a silent battle” and its respective findings. This superordinate theme captured the emotions and feelings that were acknowledged by participants as drivers for acquiring an AT for their caring role. This initial step was called “emotional triggers” because it represented the emotions that participants revealed in their inner struggles. The participants realised that the accumulation of stressors was affecting their general wellbeing (mentally or physically). Therefore, they were motivated to find an ‘alternative solution’ to their perceived problems. Several concepts from the introductory chapter in section 1.2 have been revisited to build on the discourse around ICs and new concepts have also been introduced. Bowlby’s (1969) attachment theory has been used as part of this discussion to explore some of the participants’ inner struggles.

The identified triggers

The first finding of this study indicated that caregiver burden, for the participants, increased when external stressors (such as caring for one's own children, having a job, paying bills, and so forth) accumulated with the responsibilities of their caregiving role. This means that ICs' levels of burden were affected in proportion with the degree of their responsibilities outside the caregiving role. For instance, Sofia expressed that she experienced physical, psychological, and financial burden as

she had to work full time and care for her children and mother at the same time (see section 4.3.1). This became a vicious cycle of neglecting her own needs. Not only did she feel exhausted, but she also developed psychological distress that conflicted with her overall wellbeing. Maria, Claudia, Camila, and Pablo shared similar self-neglecting patterns to a lesser degree but still experienced higher levels of perceived caregiver burden. This is consistent with the literature of the double care responsibilities (that is, caring for children and parents at the same time – see section 2.3.3), in which there are reports that ICs who have many responsibilities at once present an increased level of burden that is rooted in the conscious act of prioritising other things above their own wellbeing (Chisholm, 1999; Do et al., 2014; Jang et al., 2019). Notwithstanding this, it is important to clarify that the concept of double care responsibilities comprises just a small portion of the extensive literature on caregiver burden (Yin et al., 2002).

Another finding within the same context was that the participants' narratives were consistent with the three types of caregiver burden stated in section 2.3.3: physical, financial, and psychological. These types of burden resonate within the literature of dementia caregivers (Black et al., 2010; Ho et al., 2016; Romero-Moreno et al., 2016) and echo other studies within the field of caregiver burden which focus on those with cancer, chronic illness and HIV/AIDS (Kale & Carroll, 2016; Khanna et al., 2015; Zhang et al., 2016). In the same vein, the descriptions of physical and psychological burden from ICs of PWD in other countries, such as Uganda (e.g., Ainamani et al., 2020), Estonia (e.g., Varik et al., 2020) and China (e.g., Li et al., 2020), resonate with the experiences of the participants from this study. The next finding was that participants denied having any feelings of burden when asked directly by the researcher. Feelings of burden can be interpreted as a sign of weakness and/or shame in line with their cultural values. In section 1.2.4 and 6.2, the values of marianism and machismo were explored. Applying the rationale of marianism, a woman that complains about her responsibilities or fails to comply with them is looked down upon by society as a weak and undesirable woman because she is not embracing her femininity in terms of caring, childbearing, and submissiveness (Arevalo-Flechas, 2008). From the machismo perspective, for men, accepting that they are experiencing caregiving burden signifies a defeat and failure since they are not fulfilling their role as providers (Guilamo-Ramos et al., 2007). Therefore, results from this study revealed that the participants were strongly influenced by the cultural values of marianism and machismo since the embedded behaviours from both values informed the participants' opinions about caregiver burden.

Moreover, participants from this study felt that the accumulation of stressful responsibilities pushed them to find an alternative solution *without* asking for help or opinions from anyone. The conscious choice of not speaking up about their fears, doubts, concerns, and opinions regarding

dementia is a consistent behaviour found in studies on Latin, Hispanic and Mexican-American informal caregivers' experiences (McDermott & Mendez-Luck, 2018; Ramos-Sánchez & Atkinson, 2009). Not asking for help can be seen as an act of self-sufficiency (Ryff, 1989); however, in this research, it was interpreted as shame. The ICs in this study explained that they did not ask for help because they did not want to burden their family members unnecessarily. The participants disclosed that their family members and friends could potentially judge and/or form an idea that they were not fit for the caregiving role. The ICs felt overwhelmed by the pressure to perform well in their role since, in Mexico (as described in section 1.2.3), neglecting an older adult is punishable by law (Título Quinto del Instituto Nacional de las Personas Adultas Mayores, 2002). Therefore, if family members or friends raised suspicions of such a nature, the ICs could face a prison sentence. From a societal point of view, ICs felt pressured to fulfil their roles since failing to provide care signifies that one is a bad son/daughter (Mendez-Luck et al., 2016).

The findings from the present study diverged from Arevalo-Flechas (2014) and their research on Latino caregivers. In their work, they suggested that the Spanish language has no direct translation for the English word 'burden'. The closest translation to 'burden' is the word 'carga', which in English means 'load'. This does not have the connotation of an emotional state in the way that the word 'burden' is normally used for but a physical effect. In this research, participants did understand what 'carga' meant within this context. However, when participants were asked if they had experienced burden (directly during the interview), they all consistently denied it. Interestingly, the results from the hermeneutic analysis evidences that participants did feel burden even though they denied it at the time of the interview. For example, this was identified implicitly in the Pablo's account, he shared:

"No, people must realise that this is tearing me apart because he is a part of me. My dad is part of me. It's not ... like I'd said ... it's part of me, it's part of my life. I don't know what is going to happen when God takes him away from me". (Pablo 279-282)

The present research could potentially be compared with current and future studies on Latino caregiver burden.

The ICs from this study disclosed the hardships of accepting the parent-child role inversion. Several authors (Abraham & Stein, 2013; Cecchin, 2001; Jurkovic, 2014) have referred to this behavioural change as role reversal (the parent-child role inversion). In this study, participants who experienced the phenomenon of role reversal expressed feelings associated with grief when speaking about the subject. The subject of role reversal made participants vulnerable (for example, they cried) since they described feeling burdened by having to assume the role of parent for their PwD. The findings from this work resonated with the results from Sanders & Corley's (2003) study on ICs of PwD who experience role reversal. They concluded that ICs often develop

feelings of grief and loss as part of their assimilation process. They explained that since the parent-child life-long relationship has been altered, they are trying to find a way to self-identify and negotiate the new relationship with their parents (Sanders & Corley, 2003).

Another finding from this study revealed that ICs experienced a particular type of grief known as anticipatory grief. This concept suggests that dementia caregivers grieve the progressive loss of their affected family member through the different stages of dementia until the time of their physical death (Adams & Sanders, 2004; Blandin & Pepin, 2017; Ott et al., 2010). Lang & Fowers (2019) suggested that the reason why adult children (ICs) might experience anticipatory grief during the role reversal change is due to the strong emotional attachment to their parents. This can be explained with Bowlby's theory of attachment (1969), in which he argued that from birth, a child forms an emotional and physical attachment to their parent or caregiver as a behavioural instinct. This attachment increases the chance of the child's survival until it is safe to explore the world on their own. Furthermore, Bowlby (1982) stated that security was an underpinning of the parent-child level of attachment. The feeling of security between both stakeholders is referred to as *attachment security*, which is comprised of the parent's availability and responsiveness to the child's needs (Bowlby, 1969). In the present study, this concept correlated with the participant's anticipatory grief. In other words, participants who formed a strong bond of attachment-security during their upbringing experienced higher levels of grief. The strength of attachment of the relationships were observed in various participant's accounts. As an example, the following two quotes represent Pablo's and Camila's strong attachment to their respective parent:

"I do it from the bottom of my heart. It's not because I feel compelled to do so. No one does it out of obligation. I do everything voluntarily, but remember he is my dad. I do not know if you understand this but he gave me everything I am today. Now I have to give him back...it's just that simple." (Pablo, 243-246)

"The day that she started with dementia, I lost my best friend. She was the best. The counselor, the helper, the friend, everything, everything, everything. The confidant. When she started with dementia I lost my best friend (starts crying). [Feels like] As if someone had died, because you talk to her, but she does not care. It does not matter if you talk to her or not. You know what I mean?" (Camila, 406-410).

The literature and the findings from this study are divided regarding how attachment styles influence dementia caregivers' experiences. Several qualitative studies reported that caregivers with close relationships to their PwD had elevated levels of anticipatory grief but lower levels of caregiver burden (Carpenter, 2001; Magai & Cohen, 1998), whilst avoidant relationships reported low grief but high depression (Chang, 2019; Gillath et al., 2011). However, the findings from this study reported that regardless of the level of attachment, participants expressed constant grief, caregiving burden (implicitly) and high affinity to the utilised AT (this is explored in section 6.3.5)

After analysing the lived experiences of ICs, it can be argued that dementia is full of ambiguities. This argument is supported by decades of research with inconclusive answers in the field of dementia (James & Bennett, 2019). These include but are not limited to accurately testing for a type of dementia (Jagust et al., 2019), the right treatment for dementia and/or cure (James & Bennett, 2019), and dementia risk factors (Farfel et al., 2013; Neu et al., 2017). The inconclusive and rapidly evolving literature is confusing for caregivers, which brings more stress, since there is evidence that implies that the progression of dementia is influenced by the quality of the care given by the caregiver to the PwD. The constant pressure on the ICs pushes them to try, experiment, invent, and even change their daily routines (such as inventing games to make the PwD eat) and communication styles (such as hand gestures), in order to adapt to the stage of dementia that the PwD is in (Dupuis, 2008). In this study, ICs described how they repeatedly created and re-created activities to help them alleviate the negative behaviours of their PwD. Their attempts were reported as exhausting, stressful, and confusing. The participants could not understand why dementia was so unpredictable, they described the experience as if their PwD was physically present but psychologically gone. Frustration over dementia's unpredictable changing pace has been reported in multiple studies and it is referred to as *ambiguous loss* (Chan et al., 2020; Kean, 2010; Large & Slinger, 2015). This concept encompasses the process in which ICs physically see their PwD but are processing, in parallel, the reality that their loved one's cognitive abilities are progressively deteriorating (Boss, 2009). Dupuis (2002) explained that this is a type of loss that confuses people because it is incomplete and full of uncertainty for the families affected by it. The results from this study resonated with other studies in that participants reported feeling grief before dementia progresses (anticipatory grief), during the experience (ambiguous loss), and after the passing of their PwD (Chan et al., 2013; Frank, 2008; Holley & Mast, 2009; Sanders & Corley, 2003).

6.3.2 Step 2: Avoidance

The second step of the model is related to the findings that emerged from "the elephant in the room". It was stated in section 5.3.4 that in this superordinate, dementia was described as an emotionally charged topic that the ICs were trying to avoid speaking about. For these participants, speaking about their feelings, thoughts, and opinions was difficult because they felt guilty. This guilt was described with a variety of emotions that ranged from feeling one is not the best carer (for instance, they are not living up to the family's expectations), feeling conflicted by emotions (such as feeling both love and hate for the PwD), feeling resentful of siblings, feeling guilty for taking time for oneself, and so on. This second step represents how the participants actively tried to avoid all of these struggles (as described in step 1) that the experience of caring brought to them. All the participants made a conscious choice not to speak up about the guilt that was dragging them down, to avoid conflicts with their siblings, to avoid family divisions,

disappointments, stress, pain, and so forth.

The guilt they felt

The experience of becoming the primary caregiver of a PwD was depicted by participants as guilt and confusion being at the source of their caregiving experience. In response to the constant manifestations of guilt, participants firstly chose to remain silent about their confusing and negative emotions. This same behaviour was consistent with the results from studies about dementia caregivers' perception of guilt (Prunty & Foli, 2019; Spigelmyer et al., 2018; Wang et al., 2019). With regards to why the topic of dementia was so emotionally charged for the participants, it can be argued that culture and society had a fundamental role in how they perceived it. The results suggested two main reasons why ICs avoided speaking about dementia:

1) Wanting to appear competent, strong and good in their caring role.

The first reason was identified in participants who presented traits of familism and normalisation of traditional gender roles. These influences could explain the striving of these participants to avoid conflicts with family that could end up dividing them since both influences are highly valued behaviours in Mexico (namely, in familism, machismo, and marianism). They thought that by remaining quiet, their families would experience less burden and fewer worries and challenges since the ICs were 'coping' well without their help.

2) ICs felt isolated, feared being judged and believed no one would understand their pain.

The second reason was only used by ICs who pinpointed a coping mechanism (such as spirituality or self-efficacy) to deal with the negative feelings. To clarify these findings, participants who needed to appear like a good caregiver to avoid any conflicts or family divisions were the ones that normalised gendered behaviours and prioritised their families. The ICs who experienced negative feelings like isolation and fear developed a coping mechanism (for instance, religion) to avoid the challenges (stressors) dementia brought to their lives.

These findings are multidimensional and complex because these participants described different reasons for avoiding the subject under the same culture. This is a significant finding since Mexico is traditionally represented as a culture that relies on family support (emotionally, financially, and so on). After reviewing the literature, there are no studies of Mexican dementia caregivers that explored or explained the reasons why ICs avoided speaking about their inner struggles and doubts about dementia. However, previous studies on Hispanic/Latino dementia caregivers have reported, as separate instances, that familism (Gelman, 2014; Mendez-Luck et al., 2016; Simpson, 2010) and coping mechanisms (Balbim et al., 2019; Coon et al., 2004; Guerrero & Mendez-Luck, 2019) play a fundamental role in how ICs perceive their lived experiences with a

PwD. Furthermore, the participants indicated having a wide range of conflicting feelings about their experiences. Previous studies report that ambivalent feelings are a consistent occurrence in the literature on dementia ICs (Gilligan et al., 2015; Knight & Sayegh, 2010; Pillemer et al., 2012; Shim et al., 2012). However, most of these studies were done with spouses of PwD as opposed to the adult children in this investigation. In this study, ICs who reported ambivalent feelings were participants who described having a close relationship with their PwD. The existence of these feelings might be rooted in the many aspects related to their caregiving role, such as role reversal, dual responsibilities, the PwD's changing needs, and so on.

6.3.3 Step 3: Personal Values Assessment

The third step of the model was derived from the findings of "old habits die hard". This superordinate described the three identified ideologies that influenced all participants' experiences, namely, familism, religion, and traditional gender roles. This stage is called "personal values assessment" because during this phase, participants made a personal and internal assessment of their feelings of guilt (as described in step 2). To understand their feelings, they made sense of their experience. They realised that their culture and society had expectations about their role as a carer, family member, and citizen. Notwithstanding, this was the moment that they decided to make a change in their lives to address their inner struggles. Previous concepts that were presented in section 1.2 will be mentioned again to aid the discussion.

The importance of cultural values and beliefs

The current finding indicated that the values of familism and religion (namely, Catholicism) influenced the participants' decisions to become caregivers. This finding appears to support the literature on Latino ICs about the influence that their cultural values have on them (Arevalo-Flechas, 2008; Arévalo-Flechas et al., 2014; Neary & Mahoney, 2005). In this study, the participants that revealed religion as a reason why they became ICs of their PwD. They also expressed reasons rooted in familism. From a religious point of view, the appearance of both cultural values could be explained by the similarities between the teachings from the Catholic Church about family ideology and the value of familism (Kim & Wilcox, 2013). For example, Catholicism teaches people to respect parents in the ten commandments. It also encourages reciprocity in the form of the 'golden rule' of treating others as you want to be treated and advises respecting those who are older than yourself. Similarly, familism focuses on building close-knit families who respect, practice reciprocity, and prioritise each other (Calzada et al., 2013).

This finding points out the presence of both values (i.e., familism and religion/spirituality) in their participants. A potential explanation for this might be that previous studies were carried out in the USA with samples of Mexican-American women (Flores et al., 2019), Mexican-origin woman living in the USA (Mendez-Luck et al., 2016) and Latino and/or Hispanic, (that is, anyone from Latin America or Spain) (Gelman, 2014; Neary & Mahoney, 2005). From these studies only Gelman (2014) results found religion to be a coping mechanism, rather than a motive to become a caregiver. In this study, not all participants who indicated a sense of familism as a reason to become an informal caregiver (IC) expressed a religious motivation. Previous studies mentioned familism as the only motivation for Latin and Hispanic ICs to assume their role (Gelman, 2014; Mendez-Luck et al., 2016; Nance et al., 2018).

The present study also revealed how the traditional gender roles of machismo and marianism informed the behaviours and decision-making of ICs. The results reported that some female participants wholeheartedly accepted this societal and cultural role of carer because of the instilled value of marianism. This finding is consistent with previous studies about the impact of marianism in female Hispanic and/or Latino ICs (McDermott & Mendez-Luck, 2018; Savage et al., 2016). Another finding was that all female ICs who reported having a brother normalised their distant role of provider or casual carer (such as only calling or assisting during emergencies). This identified pattern supports Badger et al.'s (2017) findings on the cultural behaviours of Latino caregivers. These findings indicated that the value of machismo instils the role of provider in male family members. The findings from this section suggest that the Mexicans ICs who participated in this study are significantly different to the Mexicans from the studies of (McDermott & Mendez-Luck, 2018; Savage et al., 2016). A potential reason behind that is that the participants form this study are Mexicans born and living in Mexico, whilst the one from the aforementioned studies are Mexicans born and living in the United States of America. This hints at behavioural similarities between all of the studies, including the present one, but they diverge in cultural motivations and beliefs since each country has unique and changing circumstances (which may be political and social), as described in section 6.2.

6.3.4 Step 4: Self-Forgiveness

The fourth stage of the diagram encapsulates the period where ICs addressed their sense of guilt and forgave themselves by acquiring an AT to reduce their caregiver burden and/or responsibilities that resulted in gaining more personal time. This part of the experience was also derived from the subordinate "old habits die hard" since it pertains to the underpinnings that influenced the ICs to adopt their caring role and stay in the role for such a long time. As mentioned earlier in section 6.3.3, the ICs went through the process of introspection to understand their feelings of guilt (for neglecting their own physical and mental health). In the present stage, ICs

acknowledged that their feelings were affecting them emotionally and physically. Soon after the realisation, they took the initiative to make changes and/or brainstorm ideas to find alternative solutions (such as acquiring an AT) that would alleviate their caregiver burden. These participants displayed a change of attitude when they started to delegate responsibilities, accept help, and use ATs for their caring role. This change was interpreted as “self-forgiveness” since ICs managed to let go of the guilt they were carrying with them and gain more control over their lives.

Learning to let go of the guilt

The feelings of guilt were the ‘last straw’ for these participants. The accumulation of culpability and responsibilities became overwhelming to all participants. However, when they realised that their physical and mental health were compromised they decided to make a change in their role. Self-forgiveness is defined as “self-love and respect in the face of one’s own wrongdoing” (Hall & Fincham, 2005, p. 621). The findings from this research suggested that participants forgave themselves the moment they started taking care of their psychological and physical wellbeing (namely, practising self-love). Their mental health improved when ICs created the habit of making time for themselves. For example, Margarita started tennis lessons, Claudia and Maria went to therapy, Camila played the fruit machines once a week, and Sofia took some time off for holidays.

The ICs’ physical health significantly changed for the better the moment they started delegating their caregiving responsibilities. As an example, Margarita, Gloria, Pablo, and Frida decided to delegate responsibilities by hiring nurses. Camila and Valentia demanded their siblings’ support, and finally, Sofia, Claudia, and Maria decided to seek institutional care for their PwD. Similar behaviours have been identified in the literature, however, they are not described as an act of ‘self-forgiveness’ but as the informal caregivers’ self-fulfilment of ‘personal needs’ (Quinn et al., 2015; Buhr et al., 2006; Rayment et al., 2019). Some of the differences between those studies and the present study might explain the similarities and discrepancies between results. For instance, Quinn et al. (2015) reported that British ICs described needing some time off for themselves and considered arranging nursing home care for their PwD. These were two behaviours found in our research, however, Quinn et al.’s (2015) ICs did not express negative opinions about nursing homes like participants in this investigation. They also only interviewed caregivers who were spouses of the PwD. A potential explanation for this could be that the sample of British ICs consisted of individuals that claimed to be informed about interventions and governmental help – something that the Mexican ICs sample did not have. It could also be that social factors played a fundamental role into what differentiates an act of selfishness that could lead to guilt from an act of self-love and respect to oneself that can be interpreted as a personal need.

Another explanation could be that cultural factors from each country inform which dynamics are acceptable between family members and oneself. Rayment et al.'s (2019) findings indicated that the quality of the relationship between adult-child carer and parent care recipient was the determinant factor for the ICs' perceived levels of caregiver burden. If their relationship was close, it was harder for the ICs to address their own needs since they felt a duty to excel at their role. This is consistent with the findings from this study. However, in Rayment et al.'s (2019) study, participants referred to their role as a transitional and natural changing role in life, whilst in this study, it was seen as an obligation and expected behaviour. The different views justify the way ICs' caregiver burden decreases when a role is seen as a transition in life, rather than an obligation, regardless of their ethnic background. This finding hints at the importance of studying the human dimension in studies on ICs.

Finally, it was during this stage that the participants decided to purchase an AT to use it as a way of avoiding certain responsibilities (such as having to be next to the PwD at all times). The findings from this study revealed that participants felt less guilt after adopting an AT since the technology allowed them to have more independence and feel calmer and more in control of the experience (this is explored in section 6.3.5). A systematic review of ATs reducing caregiver burden in ICs led researchers to the same conclusion as the present study (Madara Marasinghe, 2015).

6.3.5 Step 5: Acceptance

The final step, "acceptance", derived from the fourth superordinate "a change of heart about the AT". In section 5.3.11, this superordinate was described as the period when ICs accepted the acquired AT into their lives. However, findings suggested that in order for participants to fully accept the ATs, they had to *previously* accept that their parent had dementia (i.e., understanding the impact of dementia in their parent's life). Therefore, this step was considered multidimensional since acceptance occurs in two ways.

- 1) ICs accept the diagnosis of dementia and what is going to happen to their PwD.
- 2) ICs accept the AT in their lives and appropriates it to fit their own needs.

This section will only focus on the first point, namely, how the participants accepted their PwD's diagnosis. This particular stage is then the precursor of the next section, section 6.4, that explores the second point, that is, how the mediating role of technology occurred in this diagram.

Making peace with dementia

This study revealed that ICs denied the diagnosis of dementia given by a health care professional because they could not comprehend the magnitude of the syndrome. In similar studies exploring the lived experiences of dementia ICs, the same results have been found (Lee et al., 2014; Neary & Mahoney, 2005; Quinn et al., 2008; Stokes et al., 2014). However, Champlin's (2018) reported that ICs did not have difficulties accepting the diagnosis of dementia. In the same vein, Bauer et al.'s (2019) study on dementia ICs from rural areas in Australia revealed that participants understood and accepted the diagnosis of dementia. However, ICs hid the diagnosis from family and friends purposively out of fear of being isolated and rejected by society since they described a persistent stigma around dementia in rural places. Although the latter study was carried out in a rural setting, the findings could be compared to the results of this study because two participants indicated that they tried to hide the strains that dementia had on their parents by using make-up and nice clothes that kept their diagnosis a secret out of fear of being judged.

In this study, it was revealed that ICs were only able to accept ATs after they had completely accepted the diagnosis of dementia (for instance, accepting how it was affecting their parent). It was explained in section 6.3.4 that when ICs acknowledged the need for a change in their lives, they decided to test ATs by using them for their caregiving role. After the changes at a personal level happened (namely, the restoration of physical and psychological wellbeing), ICs were able to accept the diagnosis. It is important to highlight at this stage that all the participants from our study bought the AT they used during their caregiving experience.

This finding supports Boots et al.'s (2015) study of ICs' acceptance of their PwD diagnosis and their results highlighting a need for a change right before the IC assimilated the illness. Moreover, after ICs had a 'testing trial' using the AT and identified positive and personal benefits, they fully accepted the ATs. This finding is consistent with the results from previous studies on ICs' AT acceptance (Fuhrer et al., 2003; Holthe et al., 2017; Pot et al., 2012). Similarly, various studies reported that ICs who felt the AT did not address their needs tended to abandon the technology (Gibson, 2019; Greenhalgh et al., 2013; Greenhalgh et al., 2015). Notwithstanding this, in all of the aforementioned studies, the authors did not disclose explicitly if the ATs were chosen by the ICs or if they were provided for the purpose of their investigation. The findings from this study revealed that when AT appropriation occurs, ICs' needs were, in effect, met by the technology. A possible explanation for these two different results could be that in the identified studies where ATs were abandoned, contextual factors were not either specified or addressed.

This explanation is consistent with the views from Greenhalgh et al. (2015), who conceded with this issue. Notwithstanding this, in the present study, in section 6.2, there was an exploration of how all ICs belonged to a generational group and how this particularity influenced the way they used and thought about ATs. As discussed earlier, their generation felt comfortable with technologies since they were accustomed to incorporating them into their daily lives, however, they were described as cautious adopters because of previous historical events that influenced their views of technology (see section 6.2). With this in mind, it could be argued that the end users' age could be a predictor of AT abandonment and adoption. The aforementioned studies (Gibson, 2019; Greenhalgh et al., 2013; Greenhalgh et al. 2015) had participants from the Silent Generation (namely, people who were born between 1925-1945 and experienced the aftermath of war and economic depression [Henger & Henger, 2012]), which could be confirmation of this speculation.

6.3.6 Summary of the Mexican informal caregiver experience with ATs

In this subsection, a five-step sequential diagram was presented that represented the identified patterns of the Mexican informal caregiver experience. The stages were: 1) emotional triggers; 2) avoidance; 3) personal values assessment; 4) self-forgiveness; and 5) acceptance, which was described as multidimensional. All the stages were described and discussed in the context of the existing literature. The following section will contain a comprehensive exploration of the mediating role of ATs during step 5. More specifically, there will be an examination of the findings pertaining to the ICs' acceptance of the ATs.

6.4 How accepting the ATs shaped the ICs role and their experience

As previously mentioned, step 5 in the diagram is multidimensional. Figure 6.4 below provides a visual representation of the acceptance of the dimensions of "diagnosis" and "AT". In section 6.3.5, there was a discussion of the process of accepting the diagnosis. This section will contain a discussion of the elements that facilitated the ICs accepting the technology and how, as a consequence, the ATs affected the ICs' role and their worldviews. This discussion was rooted in the views from postphenomenology. Postphenomenology is a contemporary philosophical movement that was created by Don Ihde (1990), with the direct influence of the perspectives of hermeneutics and pragmatism. Ihde (1990) argued that postphenomenology is concerned with understanding how technologies influence our perception of the world (hermeneutic dimension) and how technology changes what it means to be human (pragmatic dimension). Postphenomenology also focuses on the exploration of the role that technologies play as mediators of everyday experiences (Aagaard, 2017a); in other words, how technologies have the capacity to transform our lived experiences.

Section 6.4.1 contains a discussion of the elements that influenced the ICs' process of accepting the AT into their lives and the consequential emotional attachment that they developed with the technology. Bowlby's (1969) attachment theory will be used to discuss the ICs' rationale. The last two sections concentrate on an explanation of the effects of accepting the ATs in the ICs' lives and caregiving experience. Section 6.4.2 consists of a description of how the ATs mediated the experience of caring after the acceptance phase. Ihde's (1990) forms of mediation in human-technology relationships will be used to aid the interpretation. Section 6.4.3 is an examination of the dualities that exist in technology mediation and why they add an important dimension to the experience of care. Kiran's (2015) four dimensions of technological mediation will be used to discuss the identified dualities.

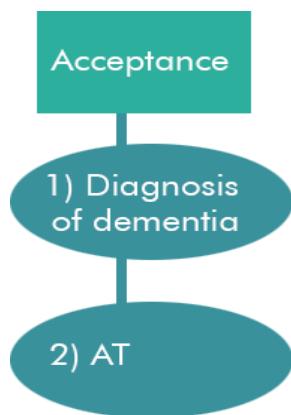


Figure 6.4 How accepting the ATs shaped the ICs role and their experience

6.4.1 Accepting the AT

The present study reported that ICs developed an affinity with the utilised AT. This interesting finding from the study indicates that after accepting the ATs in their role, participants progressively developed an emotional attachment to the technology. This was implied through the narratives of participants. For example, Gloria nicknamed her emergency button "the heart" and used descriptors attributed to the universally known heart shape (❤). Gloria's emergency button was attached to a necklace that displayed the button, hanging in front of the user's chest and it flashed a red light to announce an emergency. She defended her nickname choice by arguing that the physical resemblance between the AT and a heart was uncanny and appropriate for the experience since, just like a human heart, it was positioned at the centre of the body. She became so attached to the AT that she created a rule around it in that everyone who interacted with her mother (the PwD) had to compulsorily wear the "heart". Another example was Pablo's emotional attachment to his surveillance camera. Throughout the interview he praised the camera's features and simplicity to use. He explained how the technology gave him 'peace of mind', changing his world for the better because he was able to resume his working schedule and be outside of his

home without worrying. To him, it was sufficient for monitoring his father from his mobile phone and that convenience led him to develop an emotional bond with the technology. Perhaps, for other participants, this emotional bond developed because in such a vulnerable period in their life, ATs provided help that was free from judgement, opinions, suggestions, disagreements, or blame. The AT gave them the space to serve as a team and not as rivals. The emphasis in this argument is on how throughout the experience, ICs constantly tried to avoid anything or anyone who elevated their stress levels.

It can be argued that the AT provided the two elements that Bowlby (1969) suggested in his attachment theory (described in section 6.2.1) as essential for secure attachments: availability and responsiveness. From a dementia care perspective, secure attachments are described as the relationships in which the caregiver provides a safe, supportive, empathic, understanding, and nurturing environment for the PwD (Turan et al., 2011). In contrast, an insecure attachment is described as the ICs' self-perception of unworthiness, lack of confidence in their own actions, feeling unfit for the role, and being anxious around their PwD (Vance et al., 2008). If a caregiver forms a secure attachment with the care recipient they are more likely to have lower levels of caregiver burden than those with an insecure attachment (Gillath et al., 2011). Nelis et al. (2014) implied that emotional bonds are important for mental health and stress control during caregiving. In the attachment literature, it has been suggested that a person's, in this case the caregiver's, ability to cope and regulate their emotions during difficult circumstances is correlated to the attachment style they developed as a child (Collins, 2007). This means that ICs who developed secure attachments correspondingly display lower levels of caregiver burden, whilst those with insecure attachments consistently express higher levels (Nelis et al., 2014). Therefore, this suggests that ICs who developed an emotional bond with their AT had an insecure attachment with their PwD. This is based on the reported high levels of caregiver burden of the participants and their vocalised need to delegate tasks/withdraw from their role to care for themselves since their own needs were not being met during the experience.

Furthermore, most of the ICs described how the ATs provided them with the information they needed at times of conflict. For example, Frida used her surveillance camera to resolve arguments between her siblings by displaying recorded footage as objective evidence. In a similar vein, Valentina used her camera to record her mother with two specific purposes: 1) to provide evidence of the current health state of the PwD; and 2) to store evidence of any abuse for legal purposes. She explained during her interview that there was a point in which taking her mother to the doctor's office was impossible but she still needed her mother's medicines. She then decided to improvise and record her mother as evidence of her current physical state. This quick thinking allowed her to get her mother's prescription. Her other appropriation was to covertly record her siblings since

she suspected they were abusing her mother. The recorded material was later used during court in a legal case against her siblings. Valentina's account is a clear example of the appropriation of technology since she is using a regular technology, namely, a surveillance camera, and adjust it to fit her needs. This action resonates with the word "mexicanada" that is colloquially used in the North of Mexico to refer to an ingenious solution to a problem using improvised and limited resources (Urban Dictionary, 2016). Perhaps, this socially constructed word reflects, implicitly, the cultural need for adequate technologies since Mexico, being a low- and middle-income country (LMIC), stands behind other first world countries in the area of innovation.

Finally, it can be argued that the caregiver-AT relationship influenced the emotions, behaviours, and caregiving style of the IC. It does not appear that there are any existing studies that report dementia informal caregivers developing an attachment with the AT they used during their caring role. The most common findings around the literature of dementia ICs and ATs relate to improvements of the relationship between IC and PwD (Ekström et al., 2017; Kerssens et al., 2015) increased perception of IC individuality/freedom (Jentoft et al., 2014; Pot et al., 2012) and relief of burden (Arntzen et al., 2016; Madara Marasinghe, 2016; Mulvenna et al., 2017).

It can be concluded that ICs in this study accepted the AT when they acknowledged it brought benefits into their lives. Through constant use, the ICs developed an emotional attachment and progressive trust that shaped their behaviours and decisions during their caregiving experience. This segment contained a discussion of the elements that influenced the ICs' process of accepting the ATs into their lives. These elements were identified as the help the AT provided during the care and the convenience of availability (the ATs' ubiquity). The combination of these factors created a positive effect on the ICs' lives that consequentially led to the development of an emotional attachment with the AT. With these arguments in mind, the following subsection has a focus on exploring the impact that the newly formed human-technology relationship had over the caregiving experience and the ICs' role. This discussion will be grounded in Ihde's (1990) four forms of mediation in human-technology to provide a conceptual framework for the discourse.

6.4.2 The forms of mediation in human-technology

This study resonates with the forms of mediation in human-technology relationships stated by Ihde (1990) as part of his work in postphenomenology and described in section 2.5.3. Ihde argued that every technological artefact mediates the way in which we interact and perceive that world. He synthesised this argument as:

Human-Technology-World (p.72)

In his book *Technology and the lifeworld*, Ihde identified four types of mediating relationships: embodiment, hermeneutic, alterity and background relationships. These relationships will be discussed against the participant's accounts to identify the way ATs shaped the caregiving role.

Embodiment. This relationship was identified in some participants. For example, ICs who used surveillance cameras were able to observe their PwD through their mobile phones because the cameras transmitted the signal through the internet and displayed the footage on an app. In this case, their caregiving experience was transformed since then they were able to 'see/monitor' from any place with a wireless connection using their mobile phones app as an assistive technology. The participants who adopted surveillance cameras were able to perceive things with a visual embodiment relationship since their AT mediated the experience. The following characterisation exemplifies how the ICs used their mobile phones to see/monitor their PwD.

(IC - AT) → World

In this example, the embodiment is occurring within the brackets and the arrow represents the direction of focus, which in this case is seeing/monitoring through the technology. The AT allowed ICs to perceive the world differently because the AT acted as an extension of the ICs' eyes. The embodiment relationship, therefore, enabled the ICs to achieve different activities that were previously constrained. For example, one of the activities was that ICs were able to witness the experience without being physically there. If the ICs needed a variation of the view, through the app on their mobile phone, they were able to zoom in and out, sharpen colours, rotate the camera, and so on. This visual enhancement facilitated caring for the PwD since their behaviours were being monitored consistently with a type of peripheral vision. The new 'set of eyes' influenced the ICs' experience because the 'peripheral view' allowed them to more closely monitor the PwD's environment and how it was affecting them.

A specific example within this study is the account of Sofia, who explained that she could not find the source of a rotting smell in her mother's (PwD's) room. She decided to place a surveillance camera on a high corner wall and closely monitor all interactions anyone had with her PwD. She was able to notice, through the recordings, how her PwD hid food under the mattress whenever the person who was physically there to serve her food left the room briefly. To her, this was an eye-opening experience since she learnt this behavioural pattern and was able to respond appropriately. After this event, her caring strategy changed because she realised that she needed to be more alert and, therefore, her trust in the AT grew since it helped her with the new strategy. Thus, the AT influenced her caring role (making her aware of the environment) and overall experience (found a

way to gain more control).

Hermeneutic. In this study, ICs with monitoring cameras had to learn to read symbols displayed by their mobile phones and interpret them to learn something from the experience (for instance, when low battery was displayed it meant they had to charge their phone to continue with the experience). Similarly, the participants who wore an emergency button as a necklace had to learn to interpret what the lights and sounds from the AT meant (one blink meant an emergency, two blinks low battery, and so forth). The aim of the following representation is to synthesise how hermeneutic relationships appeared in this investigation:

IC→ (AT-World)

In the previous depiction, the ICs' focus (represented by the arrow) was on the AT which acted as the mediator between the IC and the caregiving experience (represented inside the brackets). This form of mediation is hermeneutic because the IC had to read symbols and interpret them in order to receive a representation of their experience or reality at the time. It could also be argued that ICs had to learn to read their PwD's expressions and movements to interpret whenever they needed help or attention since the AT provided, in real-time, the reality of the experience in the form of a transmission. A good example of a hermeneutic relationship from the participants' accounts is the case of Camila. She explained how, in the beginning, it was very hard for her to understand the different icons on the app that was connected to the surveillance camera. Camila bought her camera in the United States and found that everything was in English. Notwithstanding this, she disclosed that even though her English skills were basic, she was able to configure the camera. Interestingly, she struggled with a particular restriction within the app's interface – dates and the imperial system. In the United States dates, are registered mm/dd/yy, whilst in Mexico, they are dd/mm/yy. In the same vein, the imperial system is used for measurements in the United States whilst Mexico uses the metric system. This small nuance highlights the importance of cultural differences and how certain technologies have been developed to fit specific countries. Camila mentioned that this was difficult for her to convert the formats naturally in her head since she was accustomed to the Mexican formats. Another issue she encountered was that she could not find an option to change these metrics within the app. This situation affected her experience because she expressed that, on more than one occasion, she reviewed the wrong video because she forgot the American format.

Camila story resonates with Tripathi's (2018) views of technologies (these views are in line with Ihde). He argued that implementing a technology in a different cultural context creates a new way of seeing the world. With this in mind, it can be concluded that Camila's experience was mediated

by the AT because her perceptual focus of her caring role was her mobile phone (the app). She also had to learn how to read the new icons, symbols, and formats to interpret the experience. The AT also provided Camila with a hermeneutic access to the experience (caring for the PwD). It was through reading the AT that Camila was able to understand what was happening with her PwD.

Alterity. This type of relationship was identified when ICs configured any of the surveillance camera settings or reviewed the recorded videos. In their interviews, ICs explained that they interacted with their mobile phone's app in various ways, such as requesting a live stream from the camera, playing back previous recordings, programming recording periods, rotating and/or zooming the camera, and so forth. They explained that whenever they interacted with the app, they received a response from the technology in the form of a confirmation pop-up or notification. The following schematic elements illustrate the alterity relationship that was identified in the present study.

IC→ AT(-World)

In the above portrayal, the ICs focus is directly and solely on the AT (represented by the arrow). This means that the interaction is only between the IC and the AT, and the world becomes a background or contextual character. In Pablo's case, we saw how he formed a positive relationship with his AT because it interacted in a human-like way. Pablo was rational and calculated in his situation. For example, he explained that his surveillance camera had the functionality of night vision and motion sensors. He described how having these two human-like features allowed him to sleep better at night and prevent him from having to hire help for the night shift. Every night, through the camera's app, Pablo programmed a notification for each time there was movement in his father's room. Before he had the AT, he had to sleep next to his father's bed to prevent him from wandering, or he had to have someone next to his father. In short, the AT became a fundamental tool in Pablo's role, leading him to develop an attachment with the AT since it triggered positive feelings (calmness, excitement, and so on). This formed relationship shaped the way he experienced his caring role because it allowed him to relax, or gave him, as Pablo stated, "peace of mind" (Pablo, 2015). His caring role transitioned because the AT became an aid and ally in his lived experience.

Background. In this study, the identified background relationship was the surveillance camera. This AT was placed strategically inside the house and became part of the ICs' experiential background. There was no physical interaction with it, just an awareness of it, and yet, unconsciously it influenced the context of the caregiving experience. The following represents the identified relationship in this study:

IC (AT-World)

The previous representation illustrates that some ATs were in the background of the experience. It is important to clarify that the arrows have been removed for this relationship since there is no focal point from the IC. The technology and world remain inside the brackets to represent how the technology is now camouflaged into what is the world (that it is invisible but active). In this study, there were other noticeable mentions of background relationships, however, they were not ATs. For example, electricity played a fundamental role in ICs' experiences since without it, none of the ATs would have served their purpose. The ICs' internet connection and 3G signal became part of the environmental background that allowed them to utilise the ATs outside of their home. They only reported noticing these two elements when they were unavailable (for instance, in an unexpected power cut).

A relevant example is Frida's case. She had six surveillance cameras strategically placed around her PwD's home. On one hand, she expressed how the cameras became part of the house decoration and environment since no one was uncomfortable with them. On the other hand, she described how the cameras provided the 'means' for the experience because without them working 24/7, she could have had a very different experience. She said that some visitors did not notice the cameras; this was demonstrated with her mother's sister and the allegations she made against her siblings (see section 4.3.4 for more details). The following subsection will examine Kiran's (2015) four dimensions of technological mediation in relation to step 5.

6.4.3 The four dimensions of technological mediation

Following the forms of mediation in human-technology relationships from the previous subsection, four concepts were explored and related to this investigation. The focus of this subsection is on examining Kiran's (2015) four dimensions of technology mediation that were explained in section 2.5.3. According to Kiran, these dimensions' focus on identifying the two-sidedness (that is, the dualities) that delineate technological mediation. Kiran (2015) stated that the four dimensions are ontological, epistemological, practical, and ethical. Each of these dimensions is described in light of the results of the present study. All examples provided are not exhaustive and are mentioned with the intention of aiding the main arguments of each dimension. Exploring these four dimensions and two-sidedness will shed light into how the dualities within technology mediation influenced the participants' experience during step 5 (acceptance).

The ontological dimension: revealing-concealing

The participants from this study were able to *reveal* and *conceal* several aspects of their experiences. For example, the emergency button shaped the experiences of ICs. The AT was simple, in case of the button being activated, an alert was triggered to emergency services and an automated call was made to the IC and family members. It can be argued that the AT *revealed* whenever the PwD needed urgent attention (e.g., as a result of an accident). This was beneficial because there was no need to be next to the PwD 24 hours a day (since emergency services would be informed too). However, in case of the event happening, the AT *concealed* the IC from knowing the details of the emergency (what happened, how serious it was, and so forth) since the dynamics of the caregiver experience (being physically present) was changed after the adoption of the AT.

The epistemological dimension: magnification-reduction

In this study, surveillance cameras allowed the ICs to *magnify* their vision since it provided them with a peripheral view of the PwD's location and the possibility to review past recordings. It also *magnified* their hearing since some of the cameras had embedded microphones that allowed ICs to review conversations that were relevant to their role. In spite of this, the AT *reduced* the IC's use of their senses during the caregiver experience. The AT removed the ability to react to certain potential scenarios, as they spent more time away from the PwD. To a certain extent, this is detrimental to the PwD as it would be beneficial to know the care recipient's body temperature, hydration, hygiene, and so forth, which can only be measured by being in close proximity. By not being nearby as often the sense of hearing and touching are greatly *reduced* than when in the traditional IC role. The cameras also removed the ICs smell stimulus, which is critical for detecting a gas leak, for example, and which could save a person's life.

The practical dimension: enabling-constraining

A participant in this research resonated with this dimension. For example, Valentina reported that the AT *enabled* her to store images and videos as mementoes.

"...images of my mum still being my mum. She, talking with my siblings, with us, with her grandchildren, watching television because she really liked it. The most positive thing was that these mementoes were left for posterity". (Valentina, 162-166).

Notwithstanding this, another example is from Claudia who felt the ATs *constrained* her in experiencing in the flesh what became stored memories with her PwD.

"Not completely. It's never going to be the same when you're watching him[father] through a camera, than being there because you're not feeling how the mood and environment is, you're not seeing the people around hi, and the faces they are doing to him. In other words, they [technology] help you, obviously, a lot. But it is never going to be like when you are physically present. It is not the same because you miss out of precious moments"
(Claudia, 112-115).

Pablo described feeling that the AT enabled him to resume his work and have a better balance of his life since the technology allowed him to monitor his PwD from afar.

"Completely. It has taken away a weight off my shoulders. From being with him 100%, right now I can easily be less than 50% with him. I can do other things here in the house" (Pablo, 111-112).

However, in the following example, Frida felt her freedom was constrained by the condition of having to carry a mobile phone with an internet connection at all times and creating the habit of frequently checking the video transmission.

"Practically, every 40 minutes or every hour, my friends know that I'm going to check my phone to see the cameras. Also, to see if there are any messages from my siblings or my children and then I put my phone down. We are quite aware of the cameras for example, if you cannot sleep at midnight you watch them. It helps" (Frida, 84-88).

The ethical dimension: involving-alienating

In this study, an IC described covertly using surveillance cameras to monitor her siblings' interactions with their PwD. To the IC, this action enabled her to assess whether any sibling was mistreating, neglecting, or providing poor care to the PwD. In this particular case, the AT involved the IC, to a certain extent, in the care from a distance and allowed them to adopt a vigilant role. However, the AT also alienated the IC from 'real life' since she disclosed spending most of her free time monitoring her siblings' caring shifts. Her actions then posed the question of whether this covert behaviour was ethical or not. On one hand, the IC revealed abuse that she was able to record and use for legal purposes. On the other hand, this was a breach of her siblings' privacy since they did not consent to the recording. The intentions of the IC appeared to be beneficent since, in theory, the behaviour revealed a harmful action; however, from an ethical point of view the question is raised of the real intentions for the surveillance, whether it was for the PWD's safety or for their own personal gain.

6.4.4 Summary of how accepting the ATs shaped the ICs role and their experience

In this subsection, the technological dimension from step 5 was explored. Section 6.4.1 contained a description of how the ICs accepted the AT into their lives. It was stated that this occurred after personal benefits were perceived. Once the AT was accepted, it progressively shaped the ICs' role and experience. Section 6.4.2 introduced concepts from postphenomenology, the aim of which was to describe and exemplify Ihde's (1990) conceptual framework on human-technology mediations that occurred in step 5. These were embodiment, hermeneutic, alterity, and background relationships. All the types of relationships were exemplified using the results from this study. In table 6.4.4a, a synthesis of the four presented human-technology mediation relationships. From left to right, the first column displays the type of relationship, followed by the aim, the representation, and example from the present study.

Type of human-technology relationship	Aim	Representation	Example
Embodiment relationship	To mediate humans' perceptions of the world through technology	(Human-Technology) → World	(IC – Phone) → Caregiving Experience
Hermeneutic relationship	To mediate humans' perceptions of the world by interpreting a technology	Human → (Technology-World)	IC → (Phone – Caregiver Experience)
Alterity relationship	To relate a human to or with a technology, as opposed to being related to the world via a technology	Human → Technology(-World)	IC → Phone (-Caregiver Experience)
Background relationship	To exist not as a focal, foreground interaction, but in the background of perception	Human (Technology-World)	IC (Camera-Caregiving Experience)

Table 6.4.4a The types of human-technology mediation (Ihde, 1990).

Section 6.4.3 outlined the four dimensions that delineated technological mediation in the participants' lives. Table 6.4.4b illustrates the name, description of each of Kiran's (2015) dimensions, and an example provided from the study. These dimensions contained an examination of the dualities of technology mediation and exemplified them with results from this study.

Dimension	Description	Example (surveillance camera)
Ontological	This dimension refers to how technologies have changed people's worldviews.	Revealed: the abuse that <u>some</u> nurses were inflicting on their PWD. Concealed: ICs attention to other important tasks.
Epistemological	This dimension refers to how a technology shapes people's knowledge.	Magnified: ICs sight and hearing. Reduced: ICs sense of touch and smell.
Practical	This dimension refers to the way a technology shapes a person's behaviours and actions.	Enabled: ICs to resume work and have a balanced life. Constrained: ICs have to carry a mobile phone with an internet connection at all times and create the habit of checking their PWD through the app.
Ethical	The last dimension focuses on emphasising the ethical implications from the previous dimension (practical).	Involved: caring from a distance and adopting a vigilant role. Alienated: ICs from 'real life'

Table 6.4.4b The four dimensions of technological mediation (Kiran, 2015).

The next and final section concludes the chapter and synthesises the discussions on this study's findings.

6.5 Conclusion

Chapter 6 was divided into three main sections. Section 6.2 contained an exploration of the contextual factors that affected the ICs' worldviews. These were identified as historical, political, and social factors that collectively influenced the lives of participants. Section 6.3 consisted of a description of the identified stages that defined the ICs' lived experiences with ATs. These steps were: 1) emotional triggers; 2) avoidance; 3) personal values assessment; 4) self-forgiveness; and 5) acceptance. The findings of the study were outlined in each step and were discussed in the context of the existing literature. Section 6.4 contained a detailed examination of the role that technology mediation played in the final stage, "acceptance". During this extended description, concepts from postphenomenology and the four dimensions of technological mediation were examined in relation to the results of this study. In the next chapter (Chapter 7: Conclusion), the aim is to summarise the thesis by addressing the research question and objectives. There is also a description of the contributions to knowledge, as well as the implications and limitations of the research.

Chapter 7: Conclusion

7.1 Introduction

This thesis has investigated the use of assistive technologies (ATs) among informal caregivers (ICs) of a person with dementia (PwD). It used a qualitative approach in which Interpretative Phenomenological Analysis (IPA) was used to explore the role and impact of ATs in the caregiving role and caregiving experience. This led to the development of their individual accounts that revealed the complexities of their experiences with ATs. This study is relevant and significant since dementia cases around the world are expected to increase rapidly. This will be particularly worrying for low-and middle-income countries (LMICs), since their depleted health infrastructures and lack of governmental support will drive families to rely on their ICs (Alzheimer's Disease International, 2016). Therefore, this thesis plays an important role in developing a better understanding of how ATs are perceived by ICs of PwD (from a LMIC) and how ICs can use ATs to support their caring role.

The present chapter, Chapter 7, presents a final summary of the key findings in the context of the research question and research objectives. Section 7.2 focuses on demonstrating how the findings from this study answered the research question. Section 7.3 outlines the five research objectives and presents the extent to which the research achieved these objectives. Section 7.4 details the way the findings from this study extend the literature and makes a contribution to knowledge. Section 7.5 describes the methodological contributions of the study. Section 7.6 outlines the implications of the findings for policy and practice and provides suggestions that could potentially inform the government of Mexico and their health system. Section 7.7 describes the limitations that were encountered within the study and this is followed in Section 7.8, by suggestions and recommendations on how these might be overcome through future research. Section 7.9 explores the researcher's perspective for the last time during the elaboration of the thesis. Finally, Section 7.10 presents the reader with closing remarks.

7.2 Revisiting the research question

This section discusses how the following research question was addressed in this study.

How do Mexican informal caregivers of people with dementia make sense and experience their use of assistive technologies to aid their role?

The research was conducted using IPA to investigate the lived experiences of Mexican ICs of PwD who used AT for their caring role. Following the IPA methodology, data collection included in-depth interviews and the researcher's reflexivity diary.

The findings suggested that the ICs subconsciously divided the lengthy path of their care-giving experiences into two phases: pre-AT usage and AT usage. These phases were illustrated and discussed in section 6.3. During each phase, the ICs in this study made sense of the different elements that challenged and shaped their caregiver experience. Each of those elements was detailed and explored in Chapter 5. The pre-AT usage phase (sections 5.3.1-5.3.6) focused on rationalising dementia and all the events that unfolded after the diagnosis. In the second phase (section 5.3.7), which describes AT usage, the experience shifts to how the ICs' provision of care was influenced by the adopted AT.

It was also revealed that there might have been generational influences affecting the way the participants made sense of their experiences, due to specific historical, political and social factors (these are described in detail in section 6.2).

The next section will revisit the objectives of this research and will show how they were addressed.

7.3 Addressing the objectives

The overall aim of this research was to examine in detail the experiences of Mexican ICs of PwD who use ATs for their caring responsibilities. This study explored the role and impact of ATs in the caregiving role and caregiving experience in depth among a small number of ICs of PwD. Having addressed the research question above, this section will demonstrate how the research aim and objectives have been attained.

Objective 1: To explore what drives Mexican ICs to use ATs as a support in their caring role.

The research identified that the combination of three emotional triggers were the instigators for ICs to acquire an AT: 1) bearing the burden of their family members at the expense of their own wellbeing, 2) feeling stuck with the caregiver role and 3) the feelings of frustrations as a response to dementia's unpredictability. In section 5.3.1, these emotional triggers were interpreted from the participants' experiences. In section 6.2.1, the aforementioned triggers and how they relate to the literature are discussed.

Objective 2: To identify what types of ATs are being used by the participants of this study.

The results from this study pointed out that ICs from Mexico used high-tech ATs (see section 2.4.1 for detailed explanation). Four main devices were identified: surveillance cameras, baby monitors, voice recorders and emergency buttons. Most of the participants used a combination of both i.e., surveillance camera and baby monitor, surveillance camera and voice recorder (see sections 4.3.1-4.3.9). Participants who combined ATs referred to their pragmatic solution as a "mexicanada" (see section 6.4.1 for details).

Objective 3: To understand for what purpose Mexican ICs use the ATs for their role.

The study revealed that Mexican ICs used the ATs as an avoidance mechanism. The ICs reported feeling unfit for their caring role and feared being judged, misunderstood and isolated from society as a result of the many responsibilities from their role. Once the ICs realised that keeping all these feelings to themselves was compromising their physical and psychological wellbeing, they purposely purchased an AT as a way to avoid certain responsibilities (see section 5.3.2 for list of responsibilities). As a result, the ICs described that the ATs allowed them to care for their PwD within a reasonable distance and a fair way to involve all their siblings with the caring responsibility. In section 6.3.2, the benefits and consequences that emerged from using a technology for avoidance are discussed.

Objective 4: To determine what influences the perspective of Mexican ICs of PwD during their caregiver experience with ATs.

Mexican ICs were directly influenced by three ideologies: the cultural value of familism (see section 1.2.4), their personal religious beliefs (Catholicism) and traditional gender roles, which are rooted in the cultural values of machismo and marianism (section 1.2.4). It was discussed in section 6.3.3, that the combination of these three traditional elements influenced their caregiver experience before and after using ATs. It was concluded that all these ideologies were embedded and mimicked by the ICs because their parents instilled the behaviours in them and they also witnessed them in their society.

Objective 5: To identify in what way does the ATs influence the IC's role and caregiver experience.

In section 5.3.8, it was identified that the ATs influenced the IC's role by providing an increased sense of freedom and independence (since their physical presence was no longer required as before), the ability to create a routine around their (IC) needs, less guilt since siblings were now being accountable for the care (anyone could be provided with credentials to monitor the PwD) and an increased sense of bilocation (i.e. being in two places simultaneously). Section 6.4.1 discusses the aforementioned elements in relation to the literature.

In section 6.4.2, it was uncovered that the AT's significantly changed the dynamics of the caregiver experience. Before adopting the AT, the interactions with the PwD were physically one- on-one and this enabled the ICs to use all their senses to inform them about the general state of the PwD (e.g., seeing the PwD, assessing if they had a fever, etc.). After adopting the AT, the caregiver experience was mediated by the technology. A comprehensive discussion about the ways the AT mediated the experience can be found in section 6.4.2 and 6.4.3.

7.4 Contributions to knowledge

This investigation generated contributions to knowledge for the field of dementia care and technologies for dementia. None of the following contributions is claiming to be generalisable or replicable for any specific population. Instead, these contributions challenge the current assumptions made in the literature about dementia ICs from LMICs and the designs and developments of ATs with the purpose to aid ICs.

This is the first study that explored the lived experiences of Mexican ICs of PwD with ATs. This study provided an insight into what and how ICs of PwD think and feel about the ATs they used for their caregiver experience. The subjective experiences from their individual accounts for the first time have generated a better understanding of their worldviews and sense-making. This, in turn, has led to the identification of the convergences and divergences in the participants' experiences. The knowledge elicited from the analysis provided details about the experience of being an IC of a PwD in Mexico (a LMIC), the relationship that developed between ICs and ATs (and the impact it has on the IC and experience), and the internal conflicts that stemmed from specific beliefs and values around the ICs culture (highlighting the importance of exploring cultural context). Such a study has not previously been undertaken within Mexico.

7.4.1 Contributions in dementia care research

The first contribution to knowledge regards extending the psychosocial understanding about Mexican ICs of PwD. The analysis not only revealed the human dimension of their experience (e.g., emotions, perceptions, and so forth), it also untangled the complex elements that helped form the participants worldview as they incorporated the AT in their everyday lives. Section 6.3 provides a visual representation and detailed exploration of the stages that defined how the participants changed (constructed) the meanings of their experience as this progressed over time. This helps to fill the gap identified in section 2.6.1 that described the need to understand the complexities of the dementia caregiver's experience in LMICs, since only a few studies have been conducted about ICs of PwD from those countries (Fletcher, 2020; World Health Organization, 2017; Zwaanswijk et al., 2013).

Being able to granulate the complexities of each stage revealed that the decisions to become ICs of PwD from a LMIC are not exclusively derived from the shortage of nursing homes and lack of governmental support as the literature assumes (Wang et al., 2013). Instead, it demonstrated that certain human relationships and complex emotions played a role in a person becoming an IC in the context of Mexico. The understanding of the complexities of dementia caregiving expanded the literature that supports misconceptions, stigmas and religious beliefs as the main barriers to report dementia cases in LMICs (Fletcher, 2020). This study revealed that a lack of support systems (e.g., healthcare, government) for dementia patients can also be a factor for the underreporting of cases. Therefore, by understanding the psychosocial perspectives of ICs and unravelling the complexities of dementia caregiving experiences, the issues from specific LMICs could potentially be addressed.

The second contribution regards the growing body of knowledge that concentrates on understanding the impact of culture in the caregiver experience to improve dementia care in LMICs. The research literature supports the idea that culture shapes the caregiver experience (Dilworth-Anderson et al., 2002; Aranda & Knight, 1997; Knight & Sayegh, 2010). However, there was no evidence that suggests how this happens in the dementia caregiver experience in LMICs and, in particular, not in Mexico (see section 2.7.2).

In chapter 6, this study showed that cultural expectations and collective cultural meanings about dementia stemmed from core cultural values and generational influences from Mexico and they affected the ICs at various levels (e.g., sense making, behaviours, beliefs, and so forth). It was also seen that Mexican women are more likely to take on a caregiving role as a result of their embedded value of marianismo and Mexico's traditional gender roles. Marianismo is a traditional gender role and value that refers to the cultural belief that women should embrace femininity, caregiving, self-sacrifice, and suffering since they mimic the behaviours of a godly woman in the Catholic church, like the Virgin Mary (Cauce & Domenech Rodriguez, 2002). Hence, this contribution extends that Mexican women assume the role of ICs as a result of the societal pressure that they feel the need to comply with.

By identifying the ways in which culture informed the ICs provision of care and decision-making, it was then possible to trace the relationship that existed between cultural elements (e.g., how cultural expectations relate to their cultural values). Thus, this contribution suggests that, when researching the experiences of an IC in a particular context, it is important to identify the different cultural dimensions and generational influences, to discern the relations among them and evaluate the level of impact that it has on ICs and their dementia caregiver experience.

7.4.2 Contributions in technologies for dementia care

The first finding from this thesis expands our understanding in relation to technology mediation (Rosenberg and Verbeek, 2015). Through postphenomenology, empirical observations about the caregiving experience with technology were made (Ihde, 1990). This analysis advanced the knowledge about the mediating *forms* and *effects* of ATs in the dementia caregiver experience in Mexico, a LMIC using Ihde (1990) framework of human-technology relationships. The identified *forms* of mediation (see section 2.5.3 for description and 6.4.2 for discussion), demonstrated the ways in which ICs related to their ATs. The forms of mediation from Ihde (1990) helped understand how the developed relationship influenced the caregiver experience. Moreover, the mediating *effects* from Kiran (2015) revealed, for example, dualisms of experience, where the technology enabled the ICs to intensify and/or draw attention to certain elements and/or actions, whilst simultaneously distract them from others during the experience (see section 2.5.3 for description

and 6.4.3 for discussion). Identifying the mediating effects of the technology has helped to understand how the participants' pragmatically used the ATs to cope (see discussion from section 6.3.2) through their experience.

The second contribution adds to the body of knowledge in technology appropriation (Straub, 2009; Zamani et al., 2020; Aggarwal et al., 2015). The study elicited that Mexican ICs appropriated the ATs when they felt that their needs were not being met. This resonates with the literature on adaptations (Elie-Dit-Cosaque & Straub, 2011) and appropriation with caregivers (Unbehauen et al., 2020) since the ICs from this study incorporated the AT to fit their routines and daily activities. The participants made the AT fit pragmatically into their daily lives and role in a way that provided them with a perceived benefit. After incorporating the AT into their lives, the IC placed a meaning to the artefact (e.g., Gloria, in one of her quotes from p.150, she nicknamed her emergency button "the heart" and used descriptors attributed to the universally known heart shape) which changed the dynamics of the caregiving experience as a result (details in section 6.4).

The third contribution is that this study enriched our understanding about what is currently known about the kinds and use ATs for ICs in Mexico (but not necessarily and strictly of PwD) (Ilenca et al., 2017; Gibson et al., 2016; Beauregard, 2019). This topic was discussed in section 2.7.3 (Matter et al., 2017). Throughout the different individual accounts from Chapter 4 , we learnt the common types of ATs that the ICs acquired for their caring role. These were identified as surveillance cameras, emergency buttons and the combination of a surveillance camera with either a baby monitor or a voice recorder (see table 4.2.1 for a consolidated summary). Regarding the different ways in which the ICs used their ATs, in section 6.4.1, it was highlighted that a participant used the AT to objectively get information. For example, when there was a conflict between siblings, the AT (in this case a surveillance camera) displayed the recorded footage as objective evidence. Another participant used a surveillance camera to provide evidence of the current health state of their PwD and to store evidence of any abuse for legal purposes. More examples like this can be seen within section 6.4.1. It is also a contribution that the word 'mexicanada' was referred to as the act to appropriate the AT in Mexico. This concept was described in section 6.4.1 as a colloquial way to refer to an ingenious solution to a problem using improvised and limited resources (Urban Dictionary, 2016).

7.5 Methodological Contributions

This research was conducted following an IPA approach. This was the first time that IPA has been used to study the use of ATs by ICs of PwD. This methodology was found to be effective for the purpose of this investigation. Using IPA to investigate experiences with technology allowed the researcher to provide in-depth individual accounts that captured a range of relevant elements for design and development of ATs (for example, first-person accounts for designers who are interested in person-centre approach). Accordingly, this methodological contribution adds knowledge in the literature on technologies for dementia research since it facilitates the identification of the psychological aspects (human dimension) that motivate the ICs to use and appropriate the AT.

Another identified methodological contribution was that IPA provided the appropriate methods to investigate the experiences with technologies in a vulnerable and difficult to reach group. Using IPA for this study allowed the research to establish the elements that made some ICs develop an emotional attachment with their AT and how it relates to the relationship with the PwD (see section 6.4.1 for more details). Thus, IPA extends the literature in research strategies for studies that involve or have an interest in human-technology interactions/relationships, since it facilitated the elicitation of the complexities of the human dimension (which other strategies refrain from).

7.6 Implications for practice and policy

This study provides insights into the complexities that unfold from dementia caregiving in a LMIC. Two main implications were identified. The first implication pertains designers and developers of dementia technologies because the research provides a great level of detail concerning the interactions that ICs had with an AT within the technological infrastructure of a LMIC. Within the descriptions provided by the ICs, the study elicited the types, motivations, usages and purpose for the acceptance and appropriation of the AT. In addition, the study informs about the flaws and challenges raised by the ICs as part of their caregiving experience. Therefore, the ICs accounts could potentially inform designers and developers of AT for dementia about better solutions.

Moreover, the findings in relation to the experience and the meaning making from this study could potentially inform designers and developers of ATs about the types of ATs that developing countries, like Mexico, actually are using and focusing on. Previous studies that aimed at understanding end user needs, generally focused in assistive technologies that were being designed for dementia patients and nursing settings, but not the IC as one of the main stakeholders (Cila et al., 2017; Evans et al., 2015; Hwang et al., 2012). However, the present study highlighted that there is a need to understand ICs as end users too of dementia technologies and their use of ATs in their own homes. Hence, if designers and developers actually focus their attention in the specific type of ATs that ICs

from each country currently uses, like the case of Mexico, then it would be clearer the scope and ways to improve future technologies for them. For example, the ATs that participants used (e.g., monitoring cameras and emergency buttons), in Mexico might be considered by designers and developers from a high-income country as low tier technology. However, this study has proven that there is a gap in this understanding. Therefore, if designers and developers could focus in understanding why (i.e., their intentions or purpose) and how are certain ATs used by ICs in LMICs first, then a research gap could be filled regarding why are ICs chose to used particular ATs in LMICs.

The second implication could be relevant for policy makers and practitioners from countries with similar cultural values about the challenges that ICs face when seeking information and support in their caring role. It also provides key points that indicate the level of misinformation within the country; this could inform policy about better ways to create programs dedicated to increase dementia awareness and provide workshops to train family members about caregiving. The individual accounts that were developed from the ICs in this study could inform local authorities about the concerns and frustrations that ICs had during their experiences with ATs. The government's involvement may lead to significant changes, for example, a national plan for dementia that benefits the ICs, new procedures in the health sector, funding for nursing homes and support interventions that could be of use for ICs and their PwD.

7.7 Limitations of the study

Four limitations were identified in this research. The first limitation from this investigation regards the chosen research strategy: IPA. This is an approach that uses small samples and focuses on eliciting the meanings that the participants place on a particular experience (Smith et al., 2009). This poses a limitation because using a methodology that is very particular about its uses (e.g., sample size, not-theory driven and so forth) could lead researchers to adopt an extreme position about the results (Davidson & Martinsons, 2016). In the same vein, Davidson & Martinsons (2016) and Urquhart (2016), argue that when the context is particular (as in this study), a future step and a way to move towards generalisability is to move towards building theories and then extending to other contexts. Another critique about IPA is that this approach is atheoretical which can lead to concerns about the validity of results since they are not backed up by a theoretical model (Kardefelt-Winther, 2015). Further limitations of this methodology were addressed in section 3.4.2.

The second limitation identified was that only one male participant agreed to be interviewed for this investigation; while this is limiting it reflects the situation in Mexico, where much of the responsibilities for informal caregiving fall on female relatives. In addition, this study represents the experiences of a specific geographic area within Mexico. These circumstances made the most of the findings and the discussions revolved around the female perspective from one of the many regions in Mexico.

The third limitation was that only interviews were used as the method of data collection from participants. Other useful forms of collection suggested for IPA studies are the use of diaries (from the participants) and interviewing the participants more than once (Smith et al., 2009). This led to a missed opportunity of richer accounts and feedback from the ICs (as suggested by the IPA approach) that could have also identified changes through time in their experiences.

A fourth limitation was that this study did not explore and expand on the participants' developing coping skills and coping mechanisms. Although the author recognizes the importance of these coping instances within the caregiving literature, the focus of this study was centred around the use of ATs during the caregiving experience and not about how participants developed coping skills and coping mechanisms. Therefore, the author's choice was to limit the discussion to how participants developed different coping strategies as a result of their personalities and perceptual experiences by drawing upon concepts from Lazarus and Folkman (1984) coping theory.

Finally, the interviews from this study were conducted in Spanish. The quotes were translated to English for the analysis phase. It could have been possible that some of the meanings participants were trying to express were not fully represented by the linguistic incongruences between both languages. However, in section 3.4.1.3 it was stated that the researcher consulted with an expert on Mexican-Spanish discourse, to understand and translate metaphors and generational Mexican sayings. The final interpretation of these specific commonalities was discussed and approved in a meeting between the expert and the researcher who resides in Mexico.

7.8 Future research

In light of the previous limitations and with the intention to extend the findings from this research. The following suggestions are made for future research:

- 1) The current study did not investigate more than one male perspective. With the rise of the movement of gender equality and women's rights in most LMICs, there has been an increase of male caregivers within those countries (Barry, 2014). Therefore, it is suggested that future research should focus on understanding the perspectives of male caregivers; this could complement the vast literature that exists on female informal caregivers and help create support interventions for men.
- 2) It was stated in section 2.3.1 from the literature that dementia is complex, progressive and unpredictable (Brown et al., 2019). It would be useful to conduct a study with mixed methods. This could be a longitudinal study using IPA that explores the experiences of ICs of PwD with ATs over time and, through a quantitative approach, measure their levels of caregiver burden throughout the different stages of their experience. The combination

of the aforementioned methods could provide richer accounts and useful data that could extend the literature of dementia care.

3) Mexico, like many other countries in the world, have distinctive expressions and behaviours that vary from region to region within their own country (e.g., accents, idioms, beliefs, etc.). In order to conduct generalisable studies that could inform theory, it is necessary to generate and analyse empirical data from representative samples and/or build up a theory to test it in other contexts to test its validity and refine it. It is therefore suggested that a quantitative study that expands to various regions in Mexico should be conducted. Based on the findings from this study, it would be interesting for this proposed research to measure the levels of caregiver burden among ICs, their ambivalent feelings and anticipatory grief. With regard to AT use, it is suggested that data that are recorded include the following: the type of AT, their application and categorisation. The results from this proposed study have the potential to further the knowledge of the needs ICs of PwD, their motivations, purpose and appropriation of ATs in LMICs.

7.9 Closing reflexivity statement

This thesis was a challenging task at a professional, and at a personal, level. As a novice researcher, I have gained a holistic picture of what are the determinant elements of the experiences of ICs. The amount of data that I had to analyse was, at times, overwhelming and difficult to process. In the beginning of my analysis, I was affected at a personal level by some of the stories I was confided with because they were very emotionally charged and demanding. This was a challenge for me as a researcher since I had to learn how to set aside my feelings and potential biases throughout the investigation. This was the point in my journey that increased my diary entries and was subjected to numerous auditing sessions with my primary supervisor and the research group to which I belonged. Notwithstanding this, as the analysis progressed, I was able to complete the study successfully. During this concluding chapter I was able to revisit my research question and objectives that together with the previous results and discussion chapters allowed me to synthesise the findings from this extensive phenomenological research.

7.10 Closing remarks

This study provided an insight into what and how ICs of PwD think and feel about the ATs they used for their caregiver experience in Mexico. The subjective experiences from their individual accounts have provided a better understanding of their worldviews and sense-making. This, in return, led to the analysis of the convergences and divergences in the participants' experiences. The results identified the stages that Mexican ICs go through during their caregiver experience. Each stage represents key elements that influenced, challenged or struggled their dementia caregiver experience with ATs. This study was able to show the way that Mexican ICs, made sense and experienced the use of ATs to help their role. It also demonstrated the impact that ATs have on the experience as they mediate the caregiver experience. It seems fitting to conclude that this research provided ICs of PwD with an opportunity to voice their experiences and echo the importance of their invaluable contribution to society. It also showed that studying the human dimension (feelings, thoughts, culture, and so forth) when researching dementia technologies is essential since people's experiences influence directly the way ICs and PwD use and relate to the technology.

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Appendix 1 – Recruitment and participants' documentation

Recruitment email (English Version)

Dear Carer,

The Alzheimer's Association in xxxxxx is inviting you to participate in a study about informal caregivers and their use of technologies in your caring role. This investigation focuses on understanding your worldview when you are using the technology with your family member or friend affected with a type of dementia. Participation in this study is voluntary. It would involve an interview of approximately one hour at a mutually agreed location, like our offices. You are free to withdraw from the interview at any time. With your permission, the interview will be recorded and later transcribed for analysis. The leading researcher will ask you questions that relate to the way you use and think about technology. In order to participate you must meet the following characteristics:

- Your nationality must be Mexican through birth, not naturalisation.
- You should be currently using or previously used, an assistive technology in your caring role.
- You must be the primary caregiver of your family member or friend affected with a type of dementia.

All your information will be completely confidential. This means that your identity will be kept anonymous during the study.

If you are interested in participating or have any questions regarding this study, please don't hesitate to contact the researcher (see contact details below). Interviews will take place between 20th of November through the 22nd of December 2017 at a time and place convenient to you.

Yours sincerely,

Researcher's full contact details

Appendix 1 – Recruitment and participants' documentation (Continued)

Recruitment email (Spanish Version)

Estimado cuidador,

La Asociación de Alzheimer xxxxxxxx le invita a participar en un estudio sobre el uso de tecnologías en su rol de cuidador informal de un familiar con demencia. Esta investigación tiene como objetivo entender sus percepciones al utilizar tecnologías para cuidar de su familiar o amigo diagnosticado con algún tipo de demencia. Cabe destacar que la participación en este estudio es completamente voluntaria y que usted es libre de retirarse en cualquier momento si así lo desea. Este estudio consta de una entrevista con duración aproximada de una hora en un lugar acordado, por ejemplo: las oficinas de la Asociación de Alzheimer xxxxxxxx. La investigadora que llevará a cabo la entrevista, le hará preguntas relación a sus experiencias al utilizar las tecnologías, así como su percepción acerca de ellas. A fin de poder participar en dicha investigación, usted deberá cumplir con los siguientes requisitos:

- Tener la nacionalidad mexicana adquirida por nacimiento y no por naturalización
- Utilizar o haber utilizado algún tipo de tecnología asistiva en su rol de cuidador. Por ejemplo: GPS o botón de emergencia.
- Ser el cuidador principal de la persona diagnosticada con demencia

Toda su información será completamente confidencial. Esto significa que su identidad será anónima durante todo el estudio. Finalmente, se le informa que el audio de la entrevista será grabada y transcrita para posteriormente analizarse, bajo previa autorización de la persona entrevistada, es decir, usted.

En caso de estar interesado en participar o si tiene alguna pregunta sobre el estudio, no dude en contactar a la investigadora Liliana Sepúlveda García cuyos datos se encuentran al final de este correo. Las entrevistas tendrán lugar del 20 de noviembre al 22 de diciembre de 2017 a la hora y lugar de su preferencia.

Atentamente,

Liliana Sepúlveda García

Investigadora Doctoral de la Universidad de Sheffield en el Reino Unido

Nombre de la investigación: Las percepciones de cuidadores informales sobre tecnologías asistivas en la demencia: un estudio de análisis fenomenológico interpretativo (Informal Caregivers perceptions of Ambient Assisted Living Technologies for dementia: an interpretative phenomenological Analysis in Mexico)

E-mail: lmsepulveda1@sheffield.ac.uk

Whatsapp: 0075xxxxxxxx

Appendix 1 – Recruitment and participants' documentation (Continued)

Information Sheet (English Version)

The University of Sheffield Information School	Informal Caregivers perceptions of Ambient Assisted Living Technologies for Alzheimer's Disease and Related Dementias: an Interpretative Phenomenological Analysis in Mexico
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Researcher
Liliana Marisol Sepulveda Garcia

Purpose of the research
The aim of the project is to gather information on how you use technologies to care for your family member with dementia inside your home. In addition, I want to listen to your experiences using technologies and what you think of them. Your participation contributes to a PhD investigation that focuses in detailing lived experiences of Mexican informal caregivers with the use of technologies in their caring role. By detailing your perspective, stakeholders in this area could understand you better. The results from this data could potentially help understand better how culture and beliefs play an important role in technology adoption.

Who will be participating?
Mexican informal caregivers from the Mexican Federation of Alzheimer's support group in Monterrey, Mexico.

What will you be asked to do?
You will receive a questionnaire that starts with a few factual questions about yourself and then we'll proceed to have a one on one interview that will focus in your experiences with the technologies you use at home to care for your family member with dementia.

What are the potential risks of participating?
The risks of participating in this investigation are that you might feel overwhelmed or vulnerable when talking about your life experiences.

What data will we collect?
The questionnaire will be paper based with questions about your age, gender and demographics. The questions from the interview will revolve around how you use technologies at home to care for your family member with dementia and what you think about these technologies.

What will we do with the data?
All data will be stored on a password protected Google Drive folder on the University of Sheffield's secure servers. The researcher will be analyzing data for inclusion in the results section of the researcher's thesis.

Will my participation be confidential?
To ensure your anonymity, you will be assigned a pseudo name which will be used throughout the analysis. No identifying information will be retained.

What will happen to the results of the research project?
The result of the research project will be written up in a doctoral thesis and is likely be available via the University's institutional repository and accessible via the University's web pages. The study may also be reported in academic and/or professional journals and/or conferences. In all of the aforementioned circumstances, the participant's name, affiliation, position and title will never be used in relation to any of the information provided.

Appendix 1 – Recruitment and participants' documentation (Continued)

Information Sheet (Spanish Version)

The University of Sheffield. Information School	Las percepciones de cuidadores informales sobre tecnologías asistivas en la demencia: un estudio de análisis fenomenológico interpretativo.
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Nombre de la Investigadora
Liliana Marisol Sepúlveda García

Objetivo de la investigación

El objetivo del proyecto es recopilar información sobre cómo usted utiliza tecnologías para cuidar a su familiar con demencia dentro de su hogar. Por igual, quiero escuchar sus experiencias y opiniones sobre dichas tecnologías. Su participación contribuirá una investigación doctoral que se enfoca en detallar las experiencias de cuidadores informales mexicanos con el uso de tecnologías en su papel de cuidador. Al detallar su perspectiva dentro de la literatura, los interesados en esta área podrían comprender la realidad de esta experiencia en particular. Los resultados de esta investigación podrían ayudar a entender de una mejor manera cómo la cultura y las creencias juegan un papel importante en la adopción de tecnologías.

¿Quién puede participar?
Cuidadores informales de nacionalidad mexicana y personas de los grupos de apoyo de la Asociación de Alzheimer Monterrey.

¿Qué se le pedirá hacer?
Una vez que usted acepte participar, recibirá un cuestionario que comienza con algunas preguntas básicas sobre usted y posteriormente procederemos a tener una entrevista uno a uno que se centrará en sus experiencias relacionadas con el uso de tecnologías en el hogar para cuidar a su familiar con demencia.

¿Cuáles son los riesgos potenciales de participar?
Los riesgos de participar en esta investigación son que puede sentirse abrumado o vulnerable al hablar sobre sus experiencias de vida.

¿Qué datos se recopilarán?
El cuestionario previo a la entrevista, contendrá preguntas sobre su edad, sexo y características demográficas. Las preguntas de la entrevista girarán en torno a cómo utiliza las tecnologías en el hogar para cuidar al miembro de su familia con demencia y lo que piensa acerca de estas tecnologías.

¿Qué se hará con los datos?
Todos los datos se almacenarán en una carpeta protegida con contraseña en los servidores de Google Drive proporcionados por la Universidad de Sheffield. La investigadora analizará los datos para su inclusión en la sección de resultados de su tesis doctoral.

¿Mi participación será confidencial?
Para garantizar su anonimato, se le asignará un seudónimo que se utilizará durante todo el análisis. No se retendrá ninguna información que lo pudiera identificar.

¿Qué pasará con los resultados del proyecto de investigación?

El resultado del proyecto de investigación se redactarán. Los resultados de este proyecto de investigación serán incluidos en una tesis doctoral y es probable que esté disponible a través del repositorio institucional de la Universidad y accesible a través de las páginas web de la Universidad. El estudio también puede ser reportado en revistas académicas y/o profesionales y/o conferencias. En todas las circunstancias mencionadas anteriormente, el nombre, la afiliación, la posición y el título del participante nunca se usarán en relación con la información provista.

Appendix 1 – Recruitment and participants' documentation (Continued)

Consent Form (English Version)



The
University
Of
Sheffield.

Title of Research Project: Informal Caregivers perceptions of Ambient Assisted Living Technologies for Alzheimer's Disease and Related Dementias.

Name of Researcher: Liliana Marisol Sepulveda Garcia

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that my responses will be kept strictly confidential . I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
4. I agree for the data collected from me to be used in future research
5. I agree to take part in the above research project.

Name of Participant
(or legal representative)

Date

Signature

Lead Researcher

Date

Signature

To be signed and dated in presence of the participant

Note: If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, please contact Dr Jo Bates, Research Ethics Coordinator, Information School, The University of Sheffield (ischool_ethics@sheffield.ac.uk), or to the University Registrar and Secretary.

Appendix 1 – Recruitment and participants' documentation (Continued)

Consent Form (Spanish Version)

 <p>The University Of Sheffield.</p>		
<p>Título del Proyecto de Investigación: Las percepciones de cuidadores informales sobre tecnologías asistivas en la demencia: un estudio de análisis fenomenológico interpretativo.</p>		
<p>Nombre de la Investigadora: Liliana Marisol Sepúlveda García</p>		
Número de Identificación del Participante para este proyecto:	Favor de marcar la casilla	
<p>1. Confirmo que he leído y comprendido la información proporcionada que explica el objetivo del proyecto. Asimismo, confirmo que he tenido la oportunidad de preguntar dudas sobre la investigación. <input type="checkbox"/></p>		
<p>2. Entiendo que mi participación es voluntaria y que en cualquier momento Puedo retirarme de la entrevista sin necesidad de dar explicación alguna de mi decisión. De igual forma entiendo que tengo completa libertad de no contestar preguntas que me incomoden. <input type="checkbox"/></p>		
<p>3. Entiendo que mis respuestas serán estrictamente confidenciales. Otorgo autorización a los miembros del equipo de investigación a tener acceso a mis respuestas anonimizadas. Entiendo que mi nombre no estará relacionado con los materiales de investigación, y no será identificado o identificable en el informe o informes que resulten de la investigación. <input type="checkbox"/></p>		
<p>4. Acepto que los datos recopilados sobre mí sean utilizados en futuras investigaciones. <input type="checkbox"/></p>		
<p>5. Acepto participar en esta investigación. <input type="checkbox"/></p>		
Nombre del participante	Fecha	Firma
Investigador del proyecto	Fecha	Firma
<p><i>Para ser firmado y fechado en presencia del participante</i></p>		
<p>Nota: Si tiene alguna dificultad con, o desea expresar su preocupación acerca de, cualquier aspecto de su participación en este estudio, comuníquese con la Dra. Jo Bates, Coordinadora de ética de la investigación, Information School, The University of Sheffield (ischool_ethics@sheffield.ac.uk), o con el Secretario de la Universidad.</p>		

Appendix 1– Recruitment and participants’ documentation (Continued)

Demographic Questionnaire (English Version)

Demographic-Data Sheet								
Gender:	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Prefer not to say					
Age	_____							
Marital Status	<input type="checkbox"/>	Single	<input type="checkbox"/>	Married	<input type="checkbox"/>	Divorced/Separated	<input type="checkbox"/>	Widow
Do you have any children?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No				
If yes, are you their primary carer?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No				
Are you currently employed?								
<input type="checkbox"/>	Full time	<input type="checkbox"/>	Part time	<input type="checkbox"/>	Retired	<input type="checkbox"/>	Unemployed	
What is your relationship to the patient?								
<input type="checkbox"/>	Son/Daughter	<input type="checkbox"/>	Spouse	<input type="checkbox"/>	Other	Please Specify_____	(i.e: uncle, aunt, friend)	
How much time has passed since the diagnosis?								
<input type="checkbox"/>	Less than a year	<input type="checkbox"/>	A year	<input type="checkbox"/>	More than a year			
Approximately how many hours do you spend caring for your family member with dementia?								
<hr/>								
With what intended purpose do you use the technology that you use for your caring role? (You can select more than one)								
<input type="checkbox"/>	Assist in activities of daily life (i.e. Automatic blenders, electronic pillbox)							
<input type="checkbox"/>	Household up keeping (i.e. Cleaning robots, automatic thermostat, self-cleaning toilets)							
<input type="checkbox"/>	Home safety (i.e. Cameras that monitor patient, sensors that detect falls, emergency button)							
<input type="checkbox"/>	Other	Please Specify_____						

Appendix 1– Recruitment and participants' documentation (Continued)

Demographic Questionnaire (Spanish Version)

Cuestionario Demográfico	
Sexo: <input type="checkbox"/> Masculino <input type="checkbox"/> Femenino	Edad: _____
Estado Civil: <input type="checkbox"/> Soltero/a <input type="checkbox"/> Casado/a <input type="checkbox"/> Divorciado/a <input type="checkbox"/> Separado/a <input type="checkbox"/> Unión Libre <input type="checkbox"/> Viudo/a	
¿Tiene hijos? <input type="checkbox"/> Sí <input type="checkbox"/> No	¿En caso de tenerlos, viven con usted? <input type="checkbox"/> Si <input type="checkbox"/> No
¿Actualmente trabaja?	
<input type="checkbox"/> Tiempo Completo <input type="checkbox"/> Medio tiempo <input type="checkbox"/> Jubilado/a <input type="checkbox"/> Desempleado	
¿Cuál es su relación con el enfermo?	
<input type="checkbox"/> Hijo/a <input type="checkbox"/> Esposo/a <input type="checkbox"/> Otro Por favor especifique_____ (p. ej: tío, amigo, primo, etc.)	
¿Hace cuánto tiempo recibieron el diagnóstico de demencia?	
<input type="checkbox"/> Menos de un año <input type="checkbox"/> Un año <input type="checkbox"/> Más de un año	
¿Aproximadamente cuantas horas invierte en el cuidado de su familiar con demencia? _____	
¿Cuál es el propósito de la tecnología que usted adquirió para el cuidado de su enfermo? (Puede seleccionar más de una opción)	
<input type="checkbox"/> Asistir en actividades de la vida diaria (p. ej.: Cortinas automáticas, pastillero electrónico, lavadoras inteligentes, entre otras.)	
<input type="checkbox"/> Mantenimiento del hogar (p. ej. robot aspirador/aspiradora inteligente, termostato automático de temperatura ambiental)	
<input type="checkbox"/> Seguridad del hogar (p. ej. Cámaras de monitoreo, sensor de movimiento, sensor de caída, botón de caída)	
<input type="checkbox"/> Entretenimiento (p. ej. Tablet con apps que entretengan al paciente)	
<input type="checkbox"/> Otro Favor de especificar _____	
¿La tecnología que usted adquirió es con el propósito de monitorear/cuidar al enfermo? (p. ej.: un monitor de bebe que se utilice en el adulto mayor o una Tablet que ya se tenía en la casa y se usa para entretener al enfermo)	
<input type="checkbox"/> Sí <input type="checkbox"/> No	

Appendix 2 – Interview

Interview Schedule (English Version)- Page 1 of 2

Research Questions

1. Can you describe to me the technology you use?
2. Can you please tell me the story of why did you bought this technology.
 - a. Who recommended it?
 - b. Did you have any expectations about this technology before buying it? What were they?
 - c. What was the source of those expectations? (i.e films and tv, people from your support group told you)
 - d. How long have you been using it for?
 - e. How does your (family member with dementia) reacts when you are using this technology to care for him/her?
3. How does this technology help you on your activities as a carer?
 - a. How do you feel about doing (insert activity) with (insert name of technology)?
 - b. Does anyone else helps you do (insert activity)?
 - c. Can you tell me how did you manage to care for your (insert name of family member with dementia) before having this technology?
4. Can you tell me how was your relative diagnosed with dementia?
After the diagnoses, what resources were you made aware of to support your relative?
5. Could you please explain to me how did you ended being the primary caregiver of your (insert name of family member with dementia)?
6. Could you tell me about what are your concerns as a primary caregiver?
7. What does being a carer means to you?
 - a. How do you feel when you are caring? (physically, mentally and emotionally)
8. What do you think of when I say the word technology?
 - a. What does technology as a general term, means to you?
 - b. What or who do you think influenced your use of technology and how do you feel about that?
 - c. How would you describe your experiences with technologies, in general?
9. What do you think of when I say the word assistive technology?
10. Could you tell me about your best experience with this assistive technology?
11. Could you tell me about your worst experience with this assistive technology?
Tell me how you feel about using assistive technology?
12. Do you think this assistive technology has change your and your family's routine, in any way?
 - a. Do you have any concerns about this technology?
 - b. Do you trust it?

Appendix 2 – Interview (Continued)

Interview Schedule (English Version)- Page 2 of 2

13. To what extent has using this assistive technology impacted your life?
 - a. How has this affected your relationship with your extended family and friends?
 - b. Do you think your family is helping enough_ How do you feel about this?
 - c. Do you think that since you bought this technology, you have more personal time for your hobbies?
 - d. Only if they work: Can you tell me how do you balance work and caring?
 - e. Only if they have children: Can you tell me how do you balance caring for your children and (insert here name of patient)?
14. Has using assisitve technologies changed the way you relate to your (insert name of patient)? In what ways?
15. Do you think you made the right decision by buying this technology for your caring role?
 - a. Do you think that buying more equipment will change your caregiving experience? In what ways?
16. What would the ideal assistive technology do for you?
17. What would the ideal assistive technology do for (family member with dementia)?

Appendix 2 – Interview (Continued)

Interview Schedule (Spanish Version)- Page 1 of 2

Preguntas para Entrevista

1. Sería usted tan amable de proporcionarme una descripción de la tecnología que usa.
2. Me podría contar la historia acerca de cómo adquirió esta tecnología?
-Quién se la recomendó?
-Usted tenía algún tipo de expectativa sobre esta tecnología antes de adquirirla? En caso de ser así, Cuáles eran sus expectativas?
-Quién piensa usted, que pudo influenciar en sus expectativas? (por ejemplo: alguna pelicula, amigo, etc)
-Por cuánto tiempo ha utilizado esta tecnología?
-Cómo reacciona su familiar con demencia cuando usted utiliza esta tecnología para su cuidado?
3. De qué manera considera usted que esta tecnología le ayuda en sus actividades como cuidador?
-Cómo se siente cuando lleva a cabo esta actividad (menciona alguna actividad) con la tecnología?
-Alguien más de su familia le ayuda a llevar a cabo esta actividad?
-Me podría explicar cómo es que realizaba esta actividad con su familiar antes de adquirir esta tecnología?
4. Me podría narrar la historia de cómo fue que su (familiar con demencia) fue diagnosticado con demencia?
-Después del diagnóstico, qué recursos conocía usted para apoyar a su familiar con demencia?
5. Me podría narrar cómo fue que usted llegó a convertirse siendo el cuidador principal de su familiar?
6. Me podría compartir cuál es su mayor preocupación y temor como cuidador principal?
7. Qué significa para usted el ser el cuidador principal?
-Cómo se siente cuando está cuidando a su familiar? Físicamente, mentalmente, emocionalmente.
8. Qué es lo que piensa cuando le digo la palabra tecnología?
-Que significado tiene para usted la palabra tecnología y como término general?
-Qué o quién cree usted que influenció la manera en cómo piensa y usa tecnologías y cómo se siente al respecto?
-En general, cómo describiría sus experiencias con tecnologías?
9. Qué es lo que piensa cuando le digo la palabra tecnología asistiva?

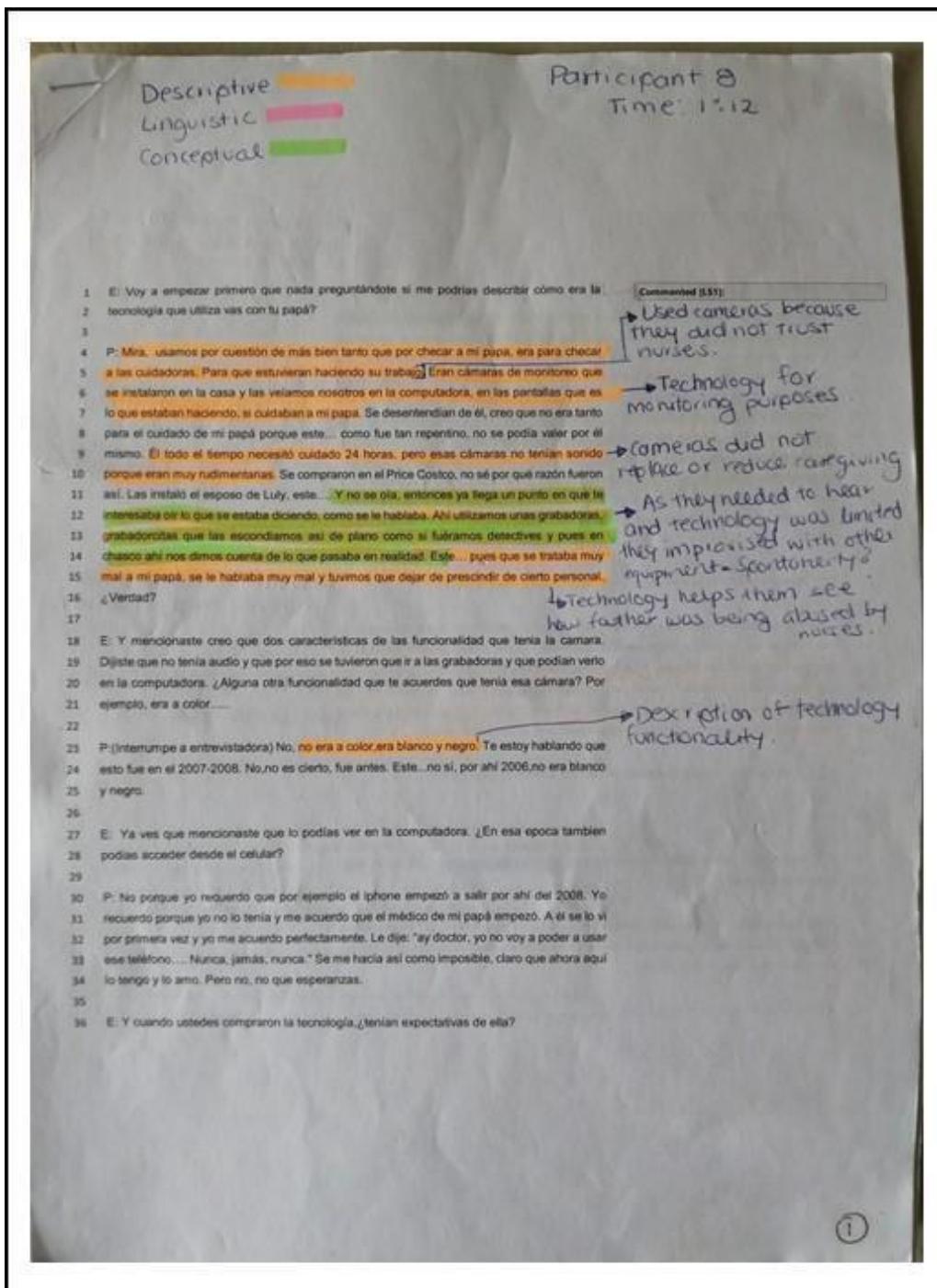
Appendix 2 – Interview (Continued)

Interview Schedule (Spanish Version)- Page 2 of 2

10. Me podría compartir cuál es la experiencia más positiva que ha tenido con esta tecnología que utiliza?
11. Me podría compartir cuál ha sido la experiencia más negativa que ha tenido con esta tecnología que utiliza?
12. Usted piensa que el uso de esta tecnología asistiva ha cambiado o alterado su rutina diaria y la de su familia? Por qué sí o por qué no?
 - Tiene alguna preocupación sobre esta tecnología?
 - Confia en ella?
13. Hasta qué grado usted opina que esta tecnología ha impactado su vida?
 - Cómo es que ha afectado su relación con su familia extendida y amigos?
 - Cree usted, que su familia está ayudando lo suficiente dentro de la casa?
 - Cómo se siente al respecto sobre esto?
 - Cree usted que desde que adquirió la tecnología, ha tenido más tiempo para sus actividades personales y pasatiempos?
 - Si es que trabaja: Me podría explicar cómo es que puede balancear su labor de trabajo y cuidado al mismo tiempo?
 - Si tiene hijos: Me podría explicar cómo es que balancea el cuidado de sus hijos y su familiar?
14. Cree usted que el usar esta tecnología asistiva ha cambiado la manera en cómo se relaciona con su familiar? En qué formas?
15. Cree usted, que hizo la decisión correcta al comprar esta tecnología para su rol de cuidador?
 - Usted cree que comprando más tecnologías podría cambiar su experiencia como cuidador? En qué maneras?
16. Cómo podría usted describir a la tecnología asistiva ideal para usted? Cuáles son las características que tendría y qué funciones tendría?
17. Cómo podría usted describir a la tecnología asistiva ideal para su familiar? Cuáles son las características que tendría y qué funciones tendría?

Appendix 3 – Idiographic Analysis

Photographic evidence of steps 1 and 2



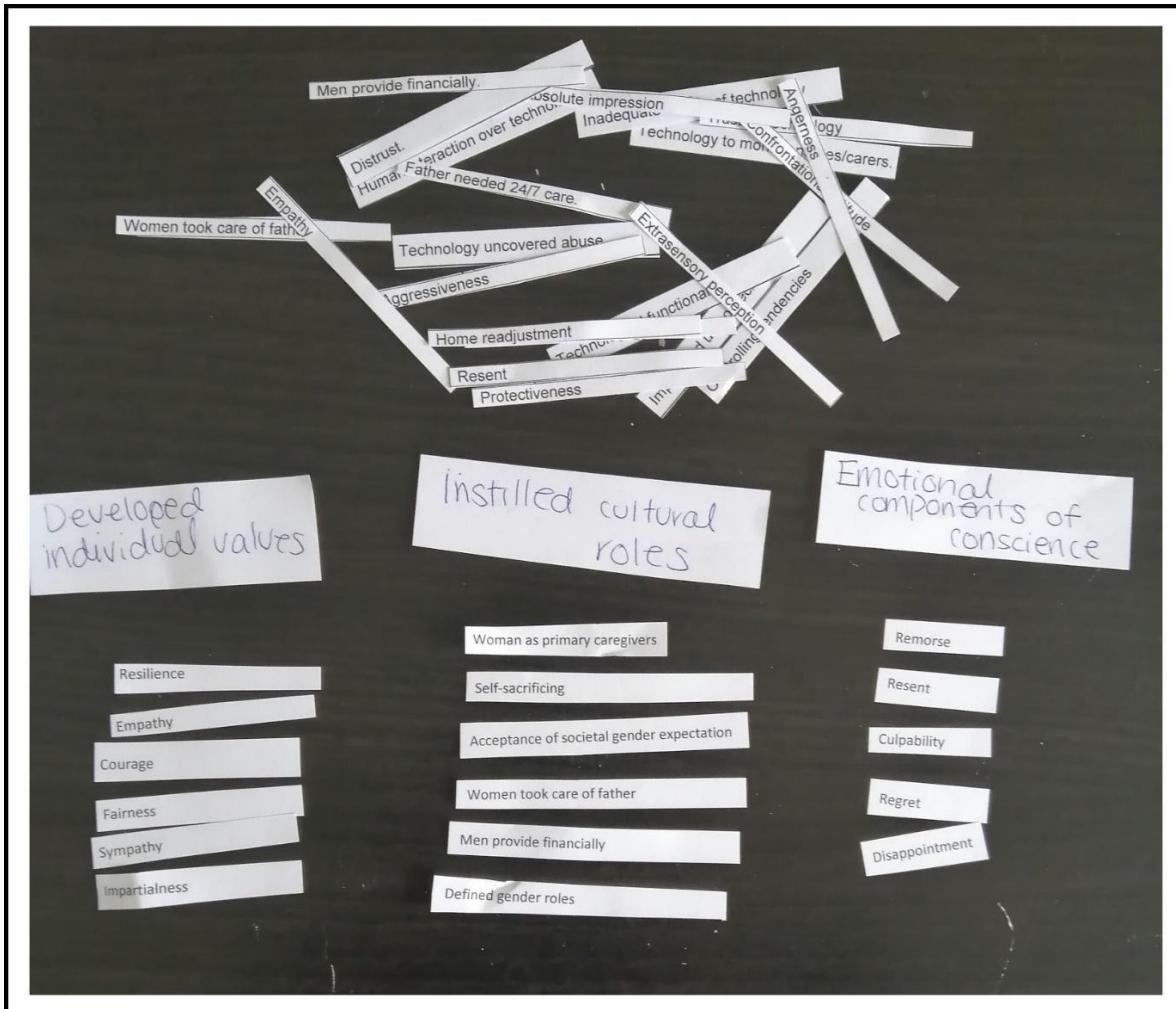
Appendix 3 – Idiographic Analysis (Continued)

Photographic evidence of step 3

Transcript	Initial Noting/Exploratory notes	Semantic Content	Line	Emergent Themes
They were closed-circuit cameras that we installed in her room and we had the main circuit in my husband's business. But later, we also used baby monitors and walkie talkies to speak with the people who were caring for my mum[at times].	Used a combination of technologies to care for her mother	descriptive	4-8	Practical/pragmatic appropriation of technology
We were twelve siblings, 8 women and 4 men. So, mainly the women were the ones that cared for my mother during the day. And at night, just one of my sisters, who is single and me. We were the ones who took care of my mum.	Females in her family assumed the role as carers. Single woman are full time only because they live in the same house with their mother.	descriptive	8-12	Woman as carers
They[cameras] were black and white and had sound. They could move from side to side. It covered the entire room very well.	Capable of describing the functionalities of the camera.	descriptive	16-18	Understands technology functionalities

Appendix 3 – Idiographic Analysis (Continued)

Photographic evidence of steps 4a



Appendix 3 – Idiographic Analysis (Continued)

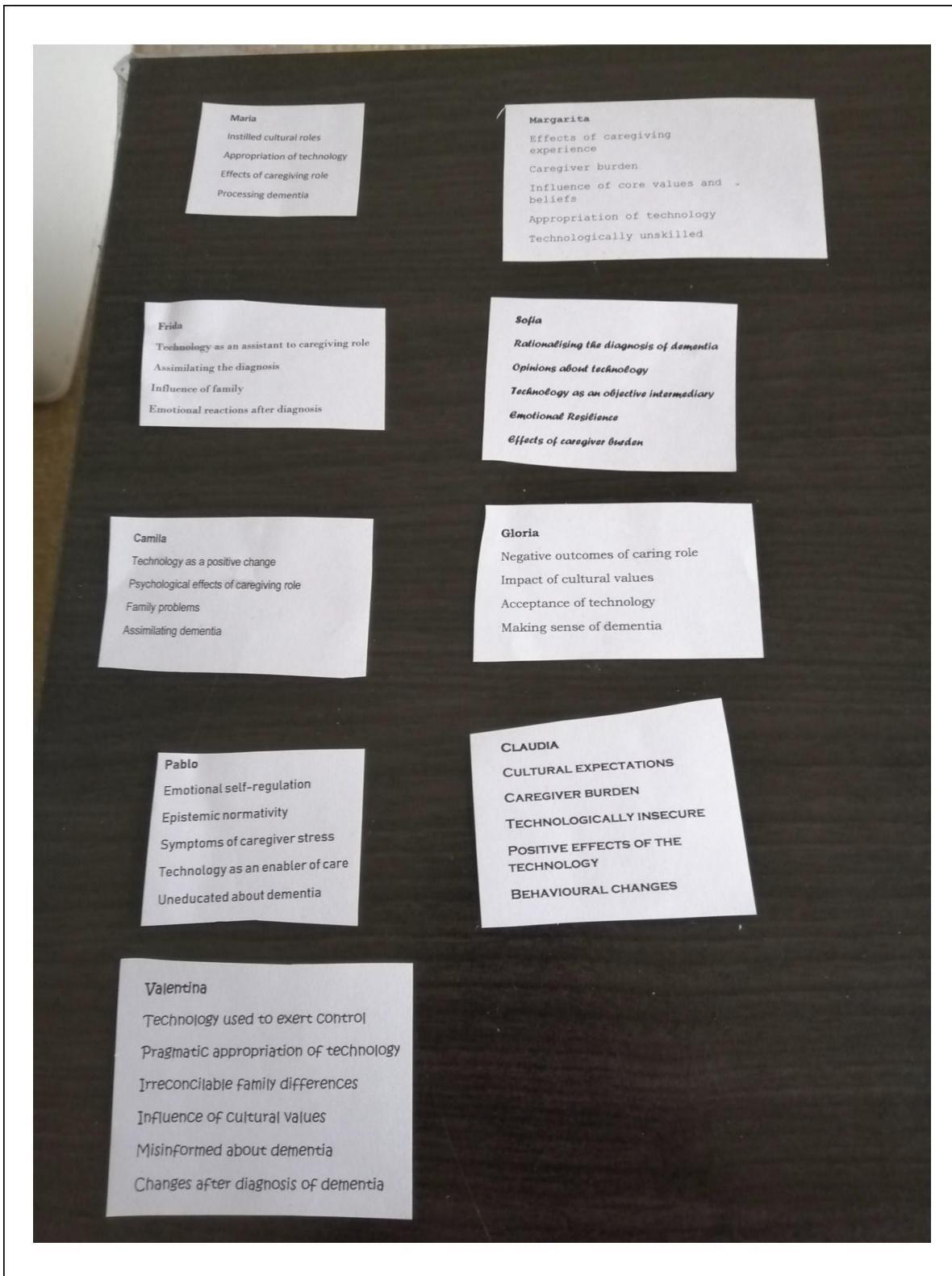
Photographic evidence of steps 4b

Cluster 1: Irreconcilable family differences		
<i>Emergent Themes</i>	<i>Line</i>	<i>Keywords</i>
Sued siblings out of fear	258-261	I had to report
Blames her siblings	290-292	They said
Afraid of siblings	160-161	Legal safeguard
Exhausted of family conflicts	261-263	Started legal problems

Cluster 2: Frustration		
<i>Emergent Themes</i>	<i>Line</i>	<i>Keywords</i>
Frustrated that siblings don't support her	255-258	Nobody supported me
Frustrated that siblings oppose her views	296-297	Mess that was made
Frustrated that no one believed her	297, 300	Believe me

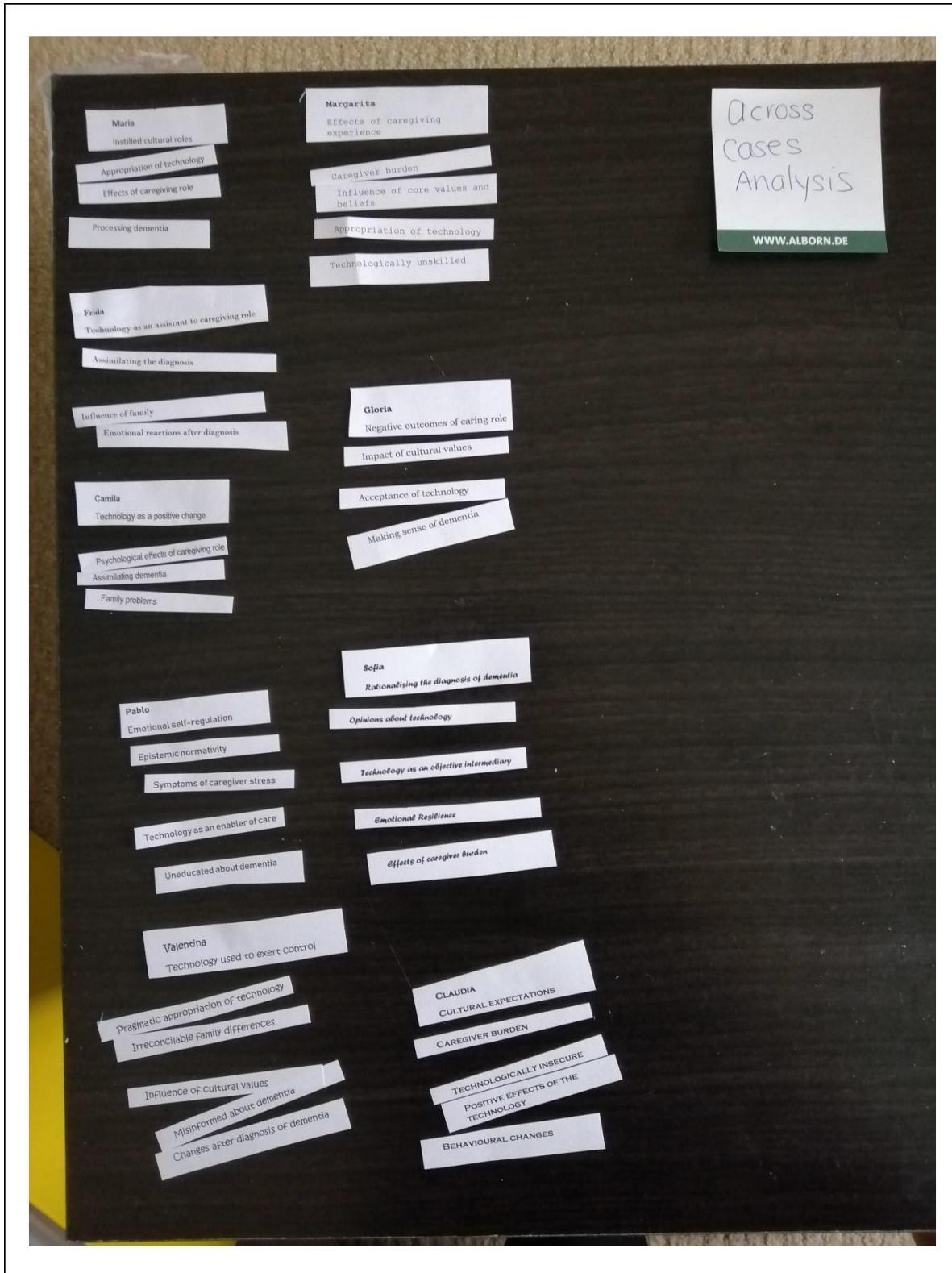
Appendix 4 – Group analysis

Photographic evidence of step 1



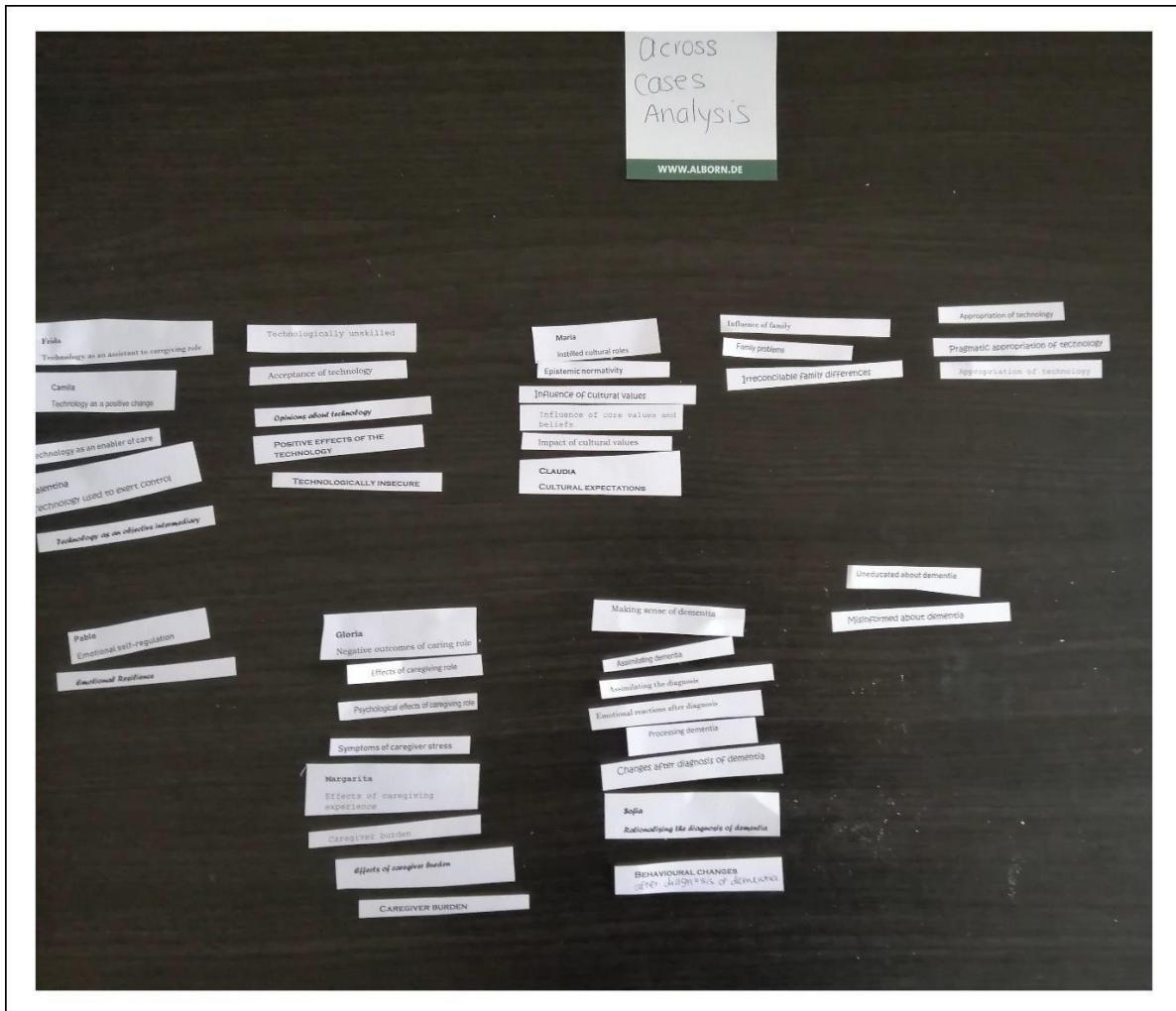
Appendix 4 – Group analysis (Continued)

Photographic evidence of step 2



Appendix 4 – Group analysis (Continued)

Photographic evidence of step 3



Appendix 4 – Group analysis (Continued)

Photographic evidence of step 4

Superordinate themes	Sofia	Claudia	Maria	Valentina	Camila	Frida	Pablo	Gloria	Margarita	Present in over half sample?
Hardships of the experience	X	X	X		X		X	X	X	YES
Assimilating the diagnosis	X	X	X	X	X	X		X		YES
Cultural influences		X	X	X			X	X	X	YES
Appropriating the technology	X		X	X		X	X		X	YES
The influence of family				X	X	X				NO
Opinions about the AT		X							X	NO
Emotional Resilience	X						X			NO
Uneducated about dementia				X			X			NO

Appendix 5 – Ethics Approval

Pilot Study



Downloaded: 15/08/2017

Approved: 15/08/2017

Liliana Sepulveda Garcia
Registration number: 150254869
Information School
Programme: INFR41

Dear Liliana

PROJECT TITLE: Informal Caregivers perceptions of Ambient Assisted Living Technologies for Alzheimers Disease and Related Dementias: an Interpretative Phenomenological Analysis in Mexico

APPLICATION: Reference Number 016013

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 15/08/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 016013 (dated 26/07/2017).
- Participant information sheet 1034658 version 2 (26/07/2017).
- Participant consent form 1034659 version 2 (26/07/2017).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Matt Jones
Ethics Administrator
Information School

Appendix 5 – Ethics Approval (continued)

Main Study



The
University
Of
Sheffield.

Downloaded: 18/10/2017

Approved: 17/10/2017

Liliana Sepulveda Garcia
Registration number: 150254869
Information School
Programme: INFR41

Dear Liliana

PROJECT TITLE: Informal Caregivers perceptions of Ambient Assisted Living Technologies for Alzheimers Disease and Related Dementias: an Interpretative Phenomenological Analysis in Mexico

APPLICATION: Reference Number 014376

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 17/10/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 014376 (dated 18/09/2017).
- Participant information sheet 1034293 version 1 (12/07/2017).
- Participant consent form 1034294 version 1 (12/07/2017).

The following optional amendments were suggested:

Please note that your ethics application has been approved with the following suggested amendments. - The following sentence should be rephrased: "No specific ethical considerations need to be in place in order to carry out this study in Mexico as this project is not dealing directly with people who have been diagnosed with dementia." I think what the researcher means is that "In Mexico, there are no specific requirements.....", however, the project must still adhere to ethical considerations relevant in the UK. Some clarity should be provided on where the interviews might take place - e.g. where are the "offices" that are referred to? - The Information sheet should make it clear that the interviews will be recorded and should explain what will happen to the recording after the interview has taken place - i.e. it will be deleted from the audio device once it has been copied to secure locations.

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Daniel Rose
Ethics Administrator
Information School