Dignity of Older People in Home-based Long-Term Care Services: a systematic review

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Abstract

Background: Dignity has been discussed in care service for decades, from health care service to long-term care services and being used as the aim of long-term care policy. However, information related to older people experiencing undignified treatments still happens consistently.

Aims: This review aimed to identify the experiences and the interpretation of older users' dignity in the process of using long-term care services.

Method: A systematic literature review was conducted to identify relevant studies primarily from the following databases: ASSIA, CINAHL, PsycINFO, Scopus, SPP, SSA, and Web of Science for English literature, and Airiti Library, TCHSS, and TPL for Taiwanese literature. Three studies were included for review after a two-step selection.

Result: A thematic synthesis approach was adopted to generate themes from the main findings of the included studies. The dignity of identity emerged to represent the situations that affect older people's lives and their interpretation of dignity. Three dimensions are listed as complements: personal dimension (self-esteem), interaction dimension (relationships) and social values, presenting the situations that affect older people's dignity from different dimensions.

Conclusion: The dignity of identity reflects older people's experiences in the long-term care system. For old home care recipients, the dignity of identity is threatened mainly. Therefore, to improve users' dignity, policymakers and service providers may need more consideration strategies to improve users' dignity.

Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

Contents

List of Tables, Figures, and Abbreviations

Contents of Tables and Figures

Abbreviations

LTC – long-term care

MOHW – Ministry of Health and Welfare (Taiwan)

NDC – National Development Council (Taiwan)

OHCHR – Office of the High Commissioner for Human Rights

SCIR – Social Care Institute for Excellence

UN – United Nations

WHO – World Health Organization

Chapter 1 Introduction

1.1 Background

Concern for human dignity has been raised in various dimensions in modern society along with the spread of an emphasis on human rights since influential global organisations promoted the concept. From a broad perspective, dignity is seen as a right that should be protected and respected (European Union, 2012). However, besides abstract discussions, personal dignity is one of the fundamental elements of a person's self-esteem and well-being (Mcleod, 2023; Care Act, 2014), which affect a person's personality integrity.

The dignity of older people has been mentioned officially for decades since the United Nations Principles for Older Persons in 1991. Along with increasing concerns for the growing care needs due to population ageing, it has been emphasised in long-term care (LTC) services and gradually in modern LTC policies (WHO Ageing and Health Programme & Memorial Fund, 2000), especially in developed European countries that developed LTC services earlier than other regions, for example, Denmark, France, Ireland and the United Kingdom who adapted dignity indicators in assessing the quality of their LTC services (The European Commission and the Social Protection Committee, 2021a, 2021b).

On the other hand, in academia and practice, interest concerning the dignity of older people occupies many research topics in different disciplines after gaining continuous attention (Lloyd et al., 2018; Nordenfelt, 2009; Haddock, 1996). Therefore, those countries determined to employ a person-centred model when delivering LTC services.

Taiwan has been affected by this trend while developing a LTC policy to respond to the foreseeable care needs resulting from the rapid population ageing speed in the late twentieth century (Wu, 2005). The government learned from the experiences of developed countries and adopted the same aims of supporting people ageing in place and living with dignity through

LTC services (Ministry of Health and Welfare, 2007; hereafter, MOHW). However, LTC services or the concept of dignity were relatively new ideas in Taiwanese society in discussing care services for older people along with the development of a LTC care system in Taiwan (Huang and Yang, 2022; Wu et al., 2004).

Moreover, examples of older people's lost dignity that Pullman (1999) and Lloyd et al. (2014) described in their studies were often observed in wards when I was a medical social worker. For instance, losing the capacity to do what they could do before or being ignored in discussions related to their care arrangement, and both situations were crucial factors for geriatric suicide (Cheng et al., 2016; Yang et al., 2014). Therefore, I doubt that the current LTC services preserved older people's dignity if it was deprived in the very beginning.

Although dignity has been a general value in most societies, it may have different interpretations in different cultural contexts (Debes, 2017; Düwell et al., 2015). Therefore, understanding what dignity indicates in the Taiwanese LTC context would be the first step to improving older service recipients' dignity since dignity has been determined as a crucial element of older people's well-being. Otherwise, the aim of preserving older people's dignity through LTC services would only be a slogan and decoration of LTC policy.

Last but not least, news and cases related to mistreatment toward older people still occur in recent years, even though this issue has been noted for decades (New9, 2018; Robb, 1967; Townsend, 1964). These remind us that dignity needs continuous attention to improve older people's well-being, especially those who have lost some capacity to speak out, even living in different societies.

1.2 Dignity in The International Convention

Dignity, a value that influences international institutions and post-war policy, was affirmed by the United Nations in the Preamble of the United National Charter in 1946. Along with disseminating the Universal Declaration of Human Rights (UDHR), dignity spread widely from legislation to various dimensions over decades (Malpas and Lickiss, 2007).

Through the UDHR and subsequent conventions, the UN shapes the typical usage and modern understanding of dignity in the declaration that: 'All human beings are born free and equal in dignity and rights' (Article 1), confirming the fundamental presumption of all human beings having inherent dignity. Subsequently, declarations, covenants or protocols related to human rights continuously adopted this value in their contents, for example, the covenant concerning eliminating all types of discrimination and the protection of the rights of different subgroups of human beings (e.g. Convention on the Rights of Persons with Disabilities, CRPD, UN, 2006).

The influence of international conventions spread fast and widely. In the political context, not only in international political documents but also in policies at the national level, the idea of dignity has been incorporated into various levels of policy law in many countries.

Shulztiner and Carmi (2014) indicated a significant increase in the number of UN member states using the term 'human dignity' in their constitutions as a fundamental value of the country and a crucial right of citizens (e.g. Germany,[1] Federal Ministry of Justice, 2021). Dignity in those political or law documents usually indicates the inherent characteristics of all human beings or is linked to human rights to emphasise the inviolable legal position. Although the property of being seen as a right remains arguable (Den Hartogh, 2014; Waldron, 2013), dignity in international political

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[1] Article 1 of the German Basic Law is a significant example for the description that 'Human dignity shall be inviolable. To respect and protect it shall be the duty of all state authority'.

organisations or a country's constitution and laws share the premise that all human beings have inherent dignity. Under this premise, the inherent dignity at the national constitution level is specifically connected to the fundamental rights of the people in a particular region, for example, a citizen of a country.[2]

However, as mentioned above, the concept of dignity has been utilised broadly because of its transmission from international organisations; from universal conventions to specific policy.

1.3 Dignity in Long-Term Care system

Along with the spread of human rights and dignity in the international community and most service users being considered as vulnerable groups, the dignity of service users became a fundamental issue of LTC systems in different level documents.

First, at the international level, the LTC system has been promoted as the proper strategy for the increasing care needs along with population ageing (World Health Organization, 2000). The document explains details of population ageing and care services using dignity in their aims – to help older people 'maintain (their) dignity' and being able to 'live with dignity', and in the principle of service delivery – to treat users with dignity (WHO, 2015).

Second, in national policy or laws, LTC policy usually adopts similar descriptions. For example, the Care Act 2014 of the United Kingdom mentioned treating people with dignity, and both Japan and Taiwan use 'maintain (citizen's) dignity' as one of the aims of providing LTC services (Article 1, Long-Term Care Insurance Act of Japan) (Japan Law Translations, 2007; MOHW, 2016).

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[2] A region is not limited to a country; for example, the charter of the fundamental rights of the European Union has a similar use of dignity in the contents, and its influence is wider than a country's constitution.

Last is the practice field, where two general dignity uses can be observed. One is the ethics codes of the professionals involved in LTC services, such as physicians, nurses, social workers and care workers. Dignity is used in the description of 'respecting dignity' as one of the principles during their work (World Medical Association, 2022; International Council of Nurses, 2021; International Federation of Social Workers, 2018; Skills for Care and Skills for Health, 2013). Another use is the indicators of quality of care for assessing service delivery.

Consider the Regulations of the Care Quality Commission (2023; hereafter, CQC) in the UK; for example, Regulation 10: dignity and respect, lists the actions of 'treating users with respect and dignity'. It includes respecting their privacy, treating them equally and supporting their autonomy, independence, and social participation. Similarly, the Social Care Institute for Excellence (SCIE) tried to introduce a more specific definition of dignity in social care (long-term care) by supporting users' self-respect, recognising their capacities, and not undermining them (SCIE, 2021).

Accordingly, dignity in LTC policies or professional ethics codes seems to start by focusing on individuals, differing from the emphasis on all human beings in conventions. Dignity in those ethics codes is closer to a property owned by a person, although the property's contents are unclear. Therefore, in practice, the professionals could be confused about what they could do to achieve the goals of respecting or improving users' dignity (Andersson and Sjölund, 2020).

However, those specific guidelines from different units are relatively concrete. Compared to the arguments concerning the abstract meaning of dignity, they still cannot represent a consensus on the meaning of dignity but reflect the possibility of interpreting dignity. On the one hand, the core of CQC and SCIE indicators are similar: respect and maintain dignity; on the other hand, they provide different approaches to reach those goals.

The different usages correspond to the temporary agreement about the characteristics of dignity, which is a multifaced concept: different conditions, situations and subjects might produce different explanations of dignity (Bedford, 2019; Clark, 2010). Moreover, several cross-country studies were conducted in Europe, providing the perspectives of older people (Tadd, 2005, 2006) related to dignified experiences in the LTC system and negative feelings. Therefore, to improve the LTC system and older care recipients' well-being, it is necessary to understand and identify how users in different contexts consider dignity during the process.

1.4 Dignity in the LTC policy in Taiwan

1.4.1 Background

The surge in the older population has raised concerns about older people's care since the 1990s (MOHW, 2007). According to projections, the proportion of older people will be over 20% of the population in seven years (2025) from 14% in 2018, when most developed countries, except the Republic of Korea and Singapore, had more than 15 years to prepare for the foreseeable increase of care needs (National Development Council, 2018). This speed of increase of older people would result in the third top share of the increase of older people with growth of 20% between 2019 and 2050, only less than the Republic of Korea (23%) and Singapore (21%) (UN, 2020).

Although not all senior citizens will have care needs, the demands for LTC services are inevitable due to the increase in the older population with a disability rate between 12–13% (MOHW, 2016).

The sharp increase in the older population, the foreseeable demand for care support and the decline of care ability of families due to the meagre total fertility rate has urged the government to establish a comprehensive LTC system to respond to the rising care needs.

A low total fertility rate combined with changes in society affecting the care

arrangement for older people is significant in Taiwan because the traditional elderly care model was bonded to the family. Similar to Japan and the Republic of Korea, living with and being cared for by an adult children's family (usually sons' families) was the primary choice of the majority of older Taiwanese people in their later lives (Koyano, 1996; Sung, 1990; Yang et al., 1988). Changes in the socio-economic environment since the 1970s have led to significant changes in the household structure and people's attitudes toward living with aged parents.

Wang and Yang (2019) indicated that the shrinking household directly affected the family care ability because of the increase of single-person, single-parent or skipped-generation households. On the other hand, Yi and Chen (1998) and Chang (1995) investigated different generations' attitudes to living with or supporting aged parents in their later lives. Both studies found a transition of attitude: more and more of the young generation preferred providing economic support instead of living with aged parents.

However, although attitudes have changed, according to the Senior Citizens Condition Survey (MOHW, 2005, 2009, 2014, 2018), living with an adult child remains the primary living arrangement for older people, while the proportion of the older generation (over 65 years old) living with spouses, living alone, living with a migrant care worker or living in facilities grew almost every year.

These trends reflect that the influence and importance of LTC systems for older people's lives will keep increasing in the future and a new stage of sharing care responsibility between state and family.

1.4.2 Dignity in the Ten-Year LTC Plan 1.0

Before developing a comprehensive nationwide LTC system, the care of older people involved the social security welfare of senior citizens, which meant that only older people in low-income households were eligible to

receive public assistance from a local government. In other situations, the family was expected to take responsibility if the senior citizen had difficulty caring for themselves (Lin, 2012; Chen, 2011).

Therefore, social policy researchers considered that the LTC policy's development was a significant sign from the government, reflecting a willingness to share care responsibility for senior citizens when they have needs. The family was not the only unit expected to take the entire responsibility, as part of the care responsibility had been transferred to the public sector (Chen et al., 2013; Lin, 2012).

The experiences of developed countries were the reference point for the structure of the LTC system. After visiting countries that had more experiences in LTC systems, including Europe (Germany, Sweden and the United Kingdom), Northern America (the United States and Canada) and Japan, and some pilot projects in several towns, the blueprint of the LTC policy was gradually completed (Wu et al., 2004; Wu and Chuang, 2005).

Considering the preferences of senior citizens, and other countries' experiences, the concept of 'ageing in place' was adopted as the primary principle of the LTC system. Accordingly, the home-based service was seen as the appropriate means to help senior citizens to stay at home for as long as possible, and the aims of improving users' independence and quality of life and maintaining their dignity for their well-being were also included in the policy (Wu et al., 2004).

The formal policy was named the Ten-Year Long-Term Care Plan (hereafter, LTC 1.0) and was implemented between 2007 and 2016. Being influenced by the policies of other countries, the use of dignity in this document is the same as the LTC policies or Acts of the developed countries. Depictions like 'establish a comprehensive long-term care system in our country, to ensure people with disability receive appropriate services, improving the ability to live independently, for maintaining dignity and autonomy' (MOHW, 2007, p.17, translated by the author) were used to describe the aim.

Dignity was used to indicate 'something' that people have, and it may change depending on situations, which was similar to the uses mentioned in the LTC policy. From this angle, the ambiguousness of dignity in the policies mentioned previously was also transplanted into Taiwanese LTC policy. The LTC system connected to the goal of maintaining dignity to portray an ideal status. However, a significant difference was the use of 'respect a person's dignity', which did not appear in LTC 1.0.

1.4.3 Dignity in the Ten-Year LTC Plan 2.0

The Ten-Year Long-Term Care Plan 2.0 (hereafter, LTC 2.0) was implemented in 2017 by a new government due to the party alternation after the presidential election in 2016. This plan was restructured by the new government according to the deficiencies of LTC 1.0, with the intention of improving the existing system to create a more comprehensive network.

Apart from the concept of 'ageing in place', which was reconfirmed as the principle for the aims of providing services, dignity was still used in the service aims. At the same time, the other parts of the plan were altered to achieve the new aim – improving quality of life. This new aim of providing LTC services would be achieved through 'a universal, affordable, and effective LTC system' (MOHW, 2016, p.48). Generally, dignity was used in the same way as in LTC 1.0 and combined with the new goal (through the LTC system) in the description:

> Providing diverse and appropriate care services to disabled citizens for their care needs, improving their capacity for living independently and (their) quality of life, maintaining their life with dignity and autonomy, for achieving the goal of ageing in place and supporting family's care ability (MOHW, 2016, p.115).

Therefore, a continuous care service including a broader range of services was emphasised, from preventive programmes to the hospice service at home. A noticeable difference was the extension to home-based palliative

care for users with terminal diseases, which could be linked to end-of-life dignity. Another new point was the importance of supporting family caregivers and improving their quality of life. Through acknowledgement of the caregiver's efforts, this new version of the plan might reflect that caregivers' dignity was also being considered in the LTC policy.

However, as characteristic of LTC policy of other countries, these new changes lacked corresponding information regarding how to help people maintain their dignity.

1.4.4 Dignity in Ethics Code of Professionals

Besides LTC policy, some professionals involved in LTC services employed sentences such as 'respect patients'/users' dignity' and 'treated patients/users with dignity', similar to those in the LTC policies, in their ethics codes as a principle for conducting their work.

In this aspect, the professional organisations in Taiwan also used dignity in their ethics codes, similar to international organisations (World Medical Association, International Council of Nurses and International Federation of Social Workers) mentioned above.

However, there were slight differences between those organisations in Taiwan. In the medical association, the principle was related to respecting patients' dignity and maintaining the professional dignity of physicians (Taiwan Medical Association, 2013), and in the ethics code of nurses, 'maintain care recipients' dignity' was a rule of professional relationships (Taiwan Union of Nurses Association, TUNA, 2023), while social workers' focuses were helping people to live with dignity and 'maintaining dignity' (Union of Licensed Social Workers, Taiwan, 2018).

Compared to the use of dignity in political and professional documents in other countries, the uses of dignity in Taiwan have yet to develop clear indicators to help practitioners connect their works and the concept of dignity. For example, 'respect care recipient's dignity' could be transferred into actions like not being neglected or experiencing discrimination (CQC, 2023).

1.5 The Research on the dignity of older people

Along with the rising concerns regarding various issues derived from population ageing, older people's dignity studies have significantly increased in recent decades. The range of topics broadly includes exploring the meaning of dignity through conceptual analyses, philosophical discussions and how older people interpret this concept and its application in LTC practice.

In broad discussions, Spiegelberg (1971), Rosen (2012) and Debes (2017) tried to identify the notion of dignity through historical and philosophical perspectives, and while Edlund et al. (2013) and Clark's (2010) studies were examples of trying to conceptualise the concept of dignity; before concerns spread to the LTC system, the dignity of patients at the end of life or with a specific disease or in a particular care setting (Torossian, 2021; Heijkenskjo et al., 2010; Nelson et al., 2010; Webster and Byran, 2009; Chochinov et al., 2008).

In the LTC system, concerns over residents' well-being were raised in institutions concerning arguments regarding total institutions (Goffman, 1968), and the service monitors and providers also adopted dignity as an essential element of quality of care, especially for institutional care. Therefore, studies concerning nursing home residents' dignity in institutional care services attracted much attention.

On the contrary, the group who receive non-residential LTC in communities was seldom the focus of the discussion about dignity in LTC (José, 2016),

although ageing at home is the primary arrangement of older people in their later lives whether their countries provide LTC or not (UN, 2021). However, reaching this group's interpretation of dignity is crucial to comprehensively understanding older people's dignity, as people's perception of dignity could vary due to factors such as culture, personality, background or roles in relationships. For example, Bentwich and colleagues (2017, 2018) noted that culture and care settings could affect a carer's interpretation of dignity; Klůzová Kráčmarová et al. (2022) and Oosterveld-Vlug et al. (2015), respectively, found that personal attitudes toward ageing and the stance in care relationships could both result in different explanations of dignity between family members of elderly users and professionals on the frontline.

On the other hand, research on older people's dignity in Taiwan is another picture that has concentrated on several fixed aspects: (i) the development of LTC policy (Wang et al., 2021; Huang and Yang, 2021; Chen and Fu, 2020; Yeh, 2019; Wu, 2017); (ii) the resource issues, including financial, human resources, community resources (Lee and Hong, 2020; Lin et al., 2017; Chen, L.C., 2016; Yang, 2014); (iii) service delivery (Tsai et al., 2021; Chiu et al., 2019; Chen, 2015); and (iv) care needs (Lin and Tsai, 2018; Chen et al., 2015; Liu, 2009; Hu, et al., 2009). Only a few studies have discussed autonomy or decision-making about moving into nursing homes and have rarely mentioned dignity (Chen and Huang, 2013; Wu et al., 2010; Lu, 1999).

Whether in a broad or limited range, the exploration of service users' dignity in non-residential LTC services is significantly less than in residential care services.

1.6 Summary

This chapter introduces the background information of this study. First, it addresses the connection between older people's dignity and LTC and the

author's motivation. The second and third parts demonstrate the changing characteristics of dignity in documents under different contexts, from the inherent dignity in international conventions to a type of fundamental rights in national constitutions and the uses in specific policy and practical documents like LTC, where it became a relatively concrete 'property' that people have and could affect their well-being when it increased or decreased according to situations.

The fourth section introduced the current LTC system in Taiwan following a similar frame from broader policy to practical fields. Demonstrating the background of LTC policy development and the uses of dignity in policy and practical documents is used to present the similarities and differences between the Taiwanese and previous uses.

The last section concisely introduces the picture of the research concerning dignity, from the broad philosophical discussions and conceptual research to studies and personal experiences about dignity in specific fields. This picture corresponds to the 'transformation' of the characteristic of dignity from abstract to relatively specific in the previous sections. Therefore, before proceeding to focus on service users' dignity in the LTC system, according to the diverse explanations, a working definition of dignity in the LTC system is a personal status underpinned by the assumption of inherent characteristics of each individual, which may fluctuate or maintain following personal situations or the interaction with others (e.g. being treated with respect).

Moreover, dignity in LTC in Taiwan is still used as a 'fixed element' of the aims but without more details about the notion, although the LTC system has stepped into its second decade in Taiwan. This lack of understanding about the dignity of older people would make 'maintain (one's) dignity' through the LTC system a slogan. For all Taiwanese, it could endanger their dignity if they were involved in the LTC system in the future. As mentioned

above, the influence of cultural context on interpreting dignity has been recognised.

In order to improve the dignity of older service recipients and their well-being, it is necessary to review the existing research concerning older users' dignity to determine if policymakers and service providers recognise the importance of dignity rather than just learning a concept from other countries.

By improving the understanding of dignity in different contexts, the LTC system can contribute to people's well-being rather than only being a tool for satisfying care needs or describing aims. Therefore, this research aims to focus on older people receiving LTC at home to explore the understanding of their dignity in the current LTC context through a review of existing research findings.

Chapter 2 Methods

2.1. Systematic Review

Various types of literature reviews have different focuses, even though some of the descriptions could be confusing from different authors because of the lack of consensus on some approaches (Colquhoun *et al.)*, 2014; Grant and Booth, 2009) and the consideration of research questions and aims is crucial to decide on review approach (Boland *et al.*, 2017).

The systematic review approach was developed to effectively review relevant evidence for healthcare clinical decision-making, including treatment selection. With the structured protocol, researchers identify relevant primary studies, appraise them critically and synthesise findings to answer a specific question or demonstrate the gap of knowledge for guiding future research (CRD, 2009). In recent decades, the application of systematic reviews has expanded across diverse fields and a more comprehensive range of purposes rather than focusing on guiding the decision-making of healthcare interventions (e.g. to produce guidance for delivery care and policy development; Lasserson *et al.*, 2022).

This research adopted a systematic review as the methodology to answer the specific question about old LTC users' dignity, which has been reviewed comprehensively in some dimensions related to the concept (Colquhoun *et al.*, 2014). Furthermore, this research aims to identify the deficiency and trend of evidence about the understanding and interpreting dignity, especially of older people who use LTC at home in practical evidence (Munn *et al.*, 2018). Moreover, dignity has been adopted in different disciplines and could have different focuses. The protocol of this approach could help researchers identify the most relevant studies from plenty of literature about dignity more effectively, minimise when synthesising for a given area and contribute to the practice measures.

2.1.1 Research Question

What is the interpretation of the dignity of older people who use non-institutional LTC services?

2.1.2 Aims and Objectives

According to the research question, this research aims to explore elderly LTC service users', families' and professionals' perspectives on older people's dignity, especially those who use home-based LTC services. The second aim is to identify the deficiency in current evidence about older people's dignity in LTC for future research. Several objectives for reaching the aim are outlined as follows:

- To explore older people's experiences and interpretations of dignity in home-based LTC services.
- To explore family members' perspectives on older people's dignity in LTC in home-based LTC services.
- To explore professionals' perspectives on older people's dignity in LTC in home-based LTC services.

2.2 Inclusion and Exclusion Criteria

Criteria are crucial for focusing on relevant research, especially since dignity has been applied broadly in various fields.

2.2.1 Inclusion Criteria

- Empirical studies related to the dignity experiences of older service users aged 60 or over in the LTC services. The type of services is home-based services such as home care, home nursing, domiciliary support and other types of non-residential care services.

- Empirical studies are about the perspectives of older users' families or professionals involved in providing LTC services (the representatives of family and professionals without age limitation). The family participants must have aged relatives who are using home-based LTC.

- Qualitative research or mixed-methods research.

Although including various types of studies in a review can provide a richer understanding, the author excluded quantitative research after a pilot search due to the considerations of different purposes between quantitative and qualitative design.

Quantitative research on dignity usually focuses on investigating dignity with defaulted options. For example, to identify the elements they established rather than to explore the potential variety of the participants' experiences on dignity (Bentwich et al., 2016; Oosterveld-Vlug et al., 2016; Kinnear et al., 2015; Deborah et al., 2013). Under this premise, the participants embed their experiences into the settled options, losing the space and opportunity to share the entire experience. Comparingly, qualitative design is a suitable approach for further exploring experiences (Creswell, 2014). Therefore, the inclusive criterion is qualitative or at least mixed research.

2.2.2 Exclusion Criteria

- Quantitative research.
- Non-primary research.
- Studies about dignity in healthcare settings (e.g. hospitals, emergency care, intensive care units and wards).
- Studies related to treatments or measures such as palliative care, end-of-life care or euthanasia.
- Irrelevant topics, such as the following:

- o Studies focus on developing therapy, treatment or quality of life.
- o Studies focus on improving practitioners' training, professional courses or discussions of ethical dilemmas.
- o Studies focus on management, workers' labour conditions and other similar topics.

- Without full texture.

The criterion of the relevant topic generally indicates a situation where dignity might be mentioned in the research but not the primary aim of the research. For example, descriptions such as 'continence improving nursing training is beneficial for patients' dignity' and 'improving supervision or continuous education for workers will also improve the users' dignity' (Fekonja et al., 2022). In these situations, dignity is a decoration of those designs of training or measures rather than the core.

2.3 Resources

As has been mentioned, the multifaceted nature of dignity has been the common conclusion in studies from different disciplines (Olsen *et al.*, 2022; Bedford, 2018; Edlund *et al.*, 2013), and culture is one of the factors that was noticed (Bentwich *et al.*, 2018).

The author conducted a previous scoping review before this systematic review which shows that most of the research on older people's dignity in LTC is in English literature, and most studies have been conducted in Western societies. Moreover, most research related to Taiwanese society has been published in Traditional Chinese Taiwanese journals that are not included in the databases of English literature. Therefore, three Taiwanese databases were included for searching literature related to Taiwan LTC due to the language consideration.

2.3.1 English Literature

Considering the research topic, and the advice of supervisors and librarian information, the databases include ASSIA, CINAHL, PsycINFO, Scopus, Social Policy and Practice (SPP), Social Science Abstracts (SSA) and Web of Science (databases: Medline and Web of science core collection).

The search terms were decided by referring to the results of a small-scale scoping review related to the research topic and discussed with supervisors, including the three main dimensions: dignity, aged and long-term care. Each dimension includes several search terms separately, as Table 2.1 demonstrates, and the Boolean term 'OR' was used between the terms in the same dimensions and 'AND' was used between different aspects. Several examples of search strategies in different databases are found in Appendix A.

Table 2.1 Search terms

Dimension	search terms
Dignity	dignity, dignified
Aged	elder*, frail*, senior*, ag*, geriatric, older people, older adult, dementia
Long-term care	social care, nursing home, residential care, supported living, home care, domiciliary care, community care

2.3.2 Taiwanese literature

Searches were undertaken on three Taiwanese databases: Airiti Library, Taiwan Citation Index-Humanities and Social Science (TCIHSS) and National Central Library Taiwan Periodical Literature (NCL Taiwan Periodical Literature, hereafter 'TPL'). The search terms were the terms or phrases used in the Taiwanese context to equally indicate the vocabulary dignity in English. Three fundamental dimensions of search terms remained, and the synonyms or acronyms in Taiwanese society were used. However, the consideration of the terms was not only the translation of English but also the usage in Taiwanese academic literature.

Table 2.2 displays the search terms used in searching Taiwanese literature. Generally, the terms were the same in different databases. The characters of Traditional Chinese were used for searching, and words in the brackets indicate the translation of English. The exception was the limitation of the search setting in TPI, which has the following limitations of searching options: a maximum of six rows for searching and cannot conduct further searching by using search history. The term in the aged dimension only used '老人' because this term located more literature than its synonyms, and this is the direct translation of older people in English and the generally used term in Taiwanese usages. Other conditions included the following: published between 2000 and January 2023, and the languages being Traditional Chinese and English.

Table 2.2 Search terms in Taiwanese databases

Dimension	search terms
Dignity	尊嚴 (dignity), 有尊嚴的(dignified)

Aged	老人, 長者, 長輩 (elder/older people/older adult)
Long-term care	長期照顧, 長期照護, 長照 (long-term care)

Language is one of the factors that led to the difference in the search process between English and Taiwanese databases; however, besides language, the different search interfaces, fields and filters also contribute to some differences between databases in searching. Brunton et al. (2017) advise that it is necessary to adjust the strategy due to the variation in these technical functionalities. In this research, the search terms remain as similar as possible, as mentioned above. The conditions of abstract, English and the published period from 2000 to January 2023 were the fundamental options between different databases.

2.4 Study Selection

Two stages of determination of the relevant studies according to the search result were conducted after removing the duplicates (Higgins and Deeks, 2011). First, the author read the title and abstracts and excluded articles according to the criteria. The second stage is processed by reading the full text; therefore, if the full text is absent, the study will be excluded at the beginning of the second stage. The relevant research would be identified by reading the content for further review and data extraction. Each stage was conducted twice at different time points, and the second time was facilitated several days after the first time. Blond *et al.* (2017) suggest this approach to reduce selection bias by a sole researcher.

2.5 Data Extraction

According to the research topic and the inclusion criteria, four papers were included finally for further reading, data extraction and analysis. Besides

the foundational research information, the decision of what data to use for extraction also referred to the research question, and the points were the care settings of LTC service. Therefore, the data extraction consisted of the following information: author, country (if the paper provides it), care settings, research design/methodology, any participants and critical findings.

However, it is noticeable that 21 papers were also listed in the extraction table, but data synthesis will not include these studies. Those papers reach most of the criteria except the type of services and the criterion of age (e.g. some studies included people under 60 years old even though the average of participants was over 60). The reason for keeping these papers is for comparison when necessary.

2.6 Quality Appraisal

The analysis of the quality appraisal provides information about the selected studies' quality, and different assessment tools have been developed for the corresponding methodology design. Along with the wide application of systematic review, various tools were developed rather than focusing on quantitative research (Hong et al., 2017). Besides the need to develop different tools for various approaches, there were arguments about using the result of appraisal of included research.

Harden and Gough (2012) indicate that quality assessment is usually conducted before a further review, and some researchers would delete a report because of a low score on quality assessment. Researchers with this viewpoint believe that research with lower quality scores will affect the reliability of a systematic review.

However, Greenhalgh and Brown (2017) argue that it depends on the researcher's intentions. Some researchers believe it might also risk deleting

helpful information despite the research quality failing to reach a high enough standard and choosing to keep the studies with low-quality assessment scores. The author will keep the studies may have some defects but no severe faults in this research.

Various appraisal tools were developed to assess the quality of studies, but there was no consensus that a single approach is preferable for all studies. CRD (2009) advises that different research considerations, such as culture, methodology and practicality, could determine the appropriate tool for a systematic review. Considering methodological and pragmatic aspects, on the one hand, the appraisal tool for qualitative research in this research is the checklist developed by the Critical Appraisal Skills Programme (CASP), which includes ten questions; on the other hand, for mixed-method research, the appraisal tool refers to Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong et al., 2018), including two screening questions and five questions for mixed method research.

The checklist is demonstrated in Appendix 2, and the result of the quality appraisal will be demonstrated in Chapter 3.

2.7 Data synthesis

The qualitative and mixed-method studies will be selected in this review according to the inclusion criteria. However, all the included studies were qualitative research. Besides the types of data, Cherry et al. (2017) suggest that the decision of the synthesis approach should accord with the research question and the purpose of the study. Moreover, the characteristics of the data also affect the choice of synthesis method (CRD, 2009).

In the systematic review approach, meta-analysis is introduced as a statistical method of combing quantitative research findings to measure the effect of interventions and selecting the appropriate intervention (Ahn and Kang, 2018; CRD, 2009). However, along with the increase of using

qualitative methods, the means qualitative meta-synthesis was also developed in health research (Paterson et al., 2001), even though many researchers considered the objectives of those methods to be related to theoretical development (Levitt, 2018; Timulak, 2008; Paterson et al., 2001).

Boland et al. (2017) indicate two general types according to the aims of the review. The aggregative review aims to assemble more descriptive findings, and the interpretative review aims to generate new interpretations (Sunzi et al., 2023; Walsh and Downe, 2004). In this research, the analysis would be closer to the aggregative one under the primary aim of this review. As mentioned above, this research aims to identify the experiences and interpretations of the dignity of older people who use home-based LTC. Therefore, through the analysis, describing and identifying the essence of human experience should be the core of analysis rather than interpreting the meaning of their experiences (Solan and Bowe, 2014).

Moreover, as Zimmer (2006) indicates, 'meta-synthesis is the synthesist's interpretation of the interpretations of primary data by the original authors of the constituent studies' (p. 312). Reflecting on the aim again, even though the objective of descriptions is also from other researchers' interpretations, the following question may need to be considered: will the reinterpretation to generate new perception make us closer to or farther away from the older people's experiences?

With those in mind, the three stages of thematic analysis approach will be adopted for analysis, including free coding through reading findings line by line, organising these 'free codes' to construct descriptive themes and developing the analytical themes (Thomas and Harden, 2008). The process and results of the thematic analysis will be demonstrated in Chapter 3.

Chapter 3 Results

Searching ten electronic databases (in two languages) yielded 2,428 studies, and 1,572 studies remained after removing duplicates. Ten studies were retained for further screening, and those that failed to meet the inclusion criteria were excluded by reviewing the title and abstracts. Six mixed-care settings studies were deleted because they included participants from healthcare and one of ten studies was excluded due to the inclusion of participants under 60 years old (Holmberg et al., 2012). Ultimately, three studies were selected, and the diagram of the process created using PRISMA, demonstrating the details of each stage and the reasons for excluding studies in the final stage, is shown in Figure 3.1.

All three papers were in English, although there were 253 papers in the initial screening of Taiwanese databases. All Taiwanese papers were excluded during the title and abstract review stage because most of the studies were classified as irrelevant. For example, they focused on topics such as 'The Application of Trust in Aged Society' (Chou, 2005), 'Natural Death, Assisted Dying and Criminal Liability' (Wang & Loh, 2010). Studies focused on the LTC policy (national or international) was the second top reason for excluding some studies, followed by other reasons like care setting (nursing homes or other residential facilities), care needs investigation, palliative care and others.

3.1 PRISMA Flow Diagram

Figure 3.1 Searching process
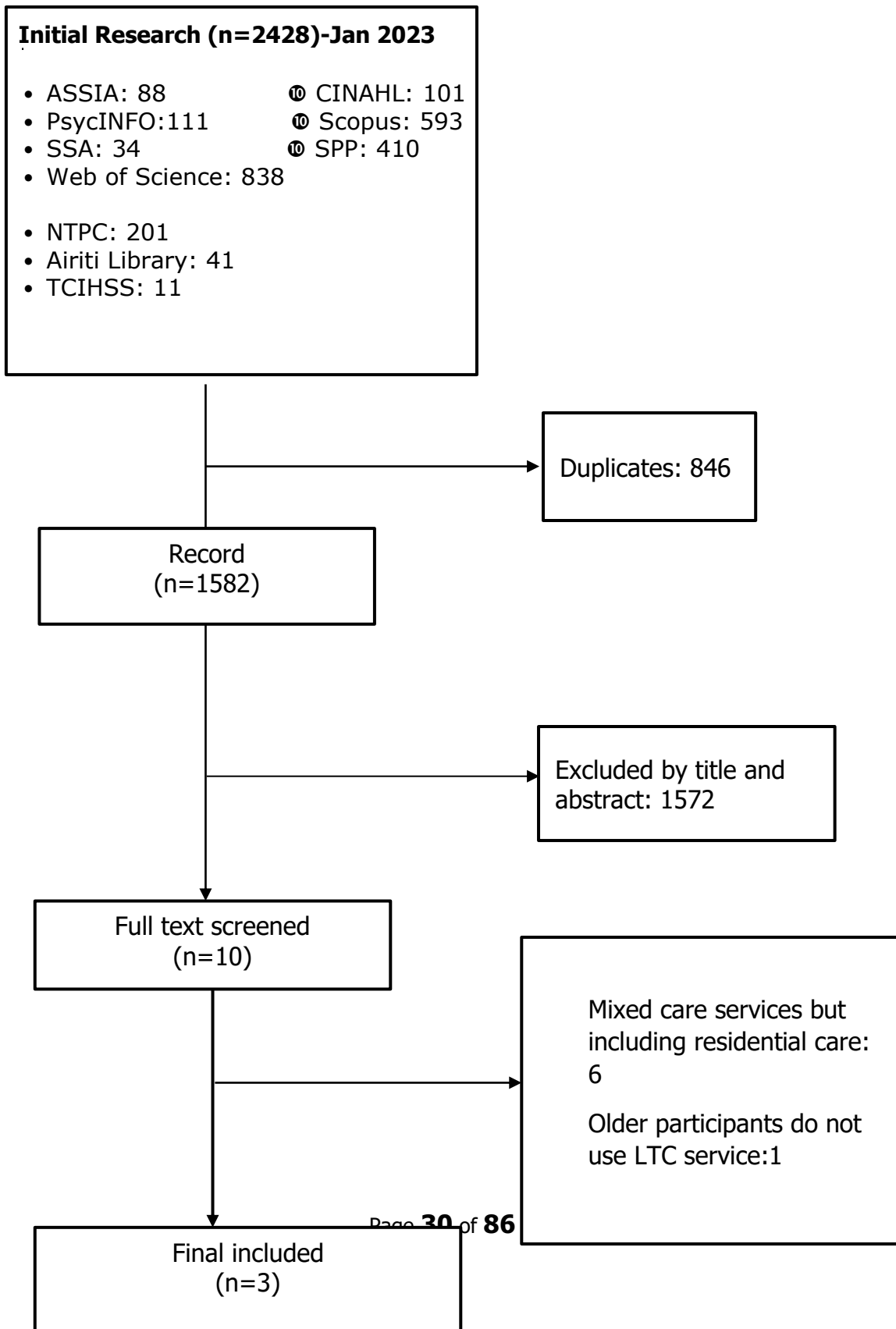
3.2 Data Extraction

Data extraction was carried out after reviewing the final selection. Relevant data from the inclusion studies are presented in Table 3.1, and the supplementary studies are listed in Table 3.2. Both tables demonstrate each study's fundamental and crucial information, including the authors' names, the countries the studies were conducted, the number of participants and their characteristics, research designs, data collection methods and key findings. In a systematic review, the extracted information from studies is beneficial to improving readers' understanding of the included studies in a short time, especially the research findings and the further discussions in subsequent sections (Fleeman & Dundar, 2017).

In this review, 18 studies as supplementary information were in Table 3.2, including a home-based care study and 17 residential care studies. The home care research met all the inclusion criteria except users' age (under 60 years old), and the 17 studies on dignity in residential LTC met all inclusion criteria except the care setting. Those studies were kept in this section to provide extra information. For example, those related to residential care may demonstrate differences in dignity between institutional and home-based care. Therefore, those studies were not included in the thematic analysis.

Table 3.1 Extraction data (home-based services)

| Author/ Country | Participants | | Research Design | Key Findings |
	Size	Characteristics		
Andersson and Sjölund (2022). Sweden	6 care unit managers and 14 care workers in four municipalities (Two large and two small)	Managers: 1. All Swedish females between 30 and 60 years of age. 2. From different backgrounds: two in social work, three in social care and one in leadership and management. 3. Experiences of management varied between two years and 18 years. Workers: 1.13 females and one male; 13 Swedish and one from Finland. 2. Age: between 17 and 60 years old. 3. Backgrounds: 13 trained auxiliary nurses, and one was in training (the youngest one).	Qualitative-case study; in-depth interviews	1. two groups of participants suggested different elements of good and dignified care: (i) managers: workers' competence, continuity, car attitude: being sensitive and flexible. (ii) workers: time and relational care, resources, skills, and specific values (e.g. empathy, respect, humanity) 2. Both managers and care workers agreed that the goal of dignified care in relevant policy usually is abstract and no guidance for service providers.
Kaldestad and Nåden (2022)/ Norway	10	1. Age: ranging in age from 66 to 91 with an average of 82 years. 2. All female who live alone and use municipal home care for a physical disease.	Qualitative research based on Gadamer's ontological hermeneutics; interview two times	1.Two themes: (i)Confirming encounters provide human dignity: being seen and listened to in the process making participants feel cared for and respected; (ii) Not being confirmed as a human being violates human dignity: e.g. the nurses not care about the

				user as an individual, absence of meeting, less continuity. 2. Participants'' dignity is shown in the quality of the meeting with the nurses, both in the conversation and through touch in the care.
		3. Experiences of home care services: from 3 months to 10 years; the average was 6.6 years.		
José (2016) /Portugal	24	1. Age: 3 under 75 years, 10 between 76 and 86 years, and 11 aged over 86. 2. 10 male and 14 female. 3. All the participants were receiving both professional home care and family care.	Qualitative; **participant observation** (were conducted in the elders' homes, as we accompanied the home care workers on their visits); **informal conversation**: occurred during the observations in the elders' homes and on other occasions, such as when the researchers and home care workers were travelling to the care receivers' homes.	1. Loss of dignity is the major concern of older people, driving from loss of control over body functions, and receiving care. These losses assault particularly the dignity of identity and human dignity. 2. Five modes of preserving dignity: (a) keeping going, (b) sheltering in personal spaces, (c) reaffirming power, (d) cherishing the caregivers (e) disconnecting from life. 3. Preserving dignity is shaped by both micro and macro contexts. 4. The selection of preserving strategy is influenced by two subjective evaluation processes (*inventorying what one still has* and *judging the worthiness of living*), which shaped by the elder's internal and external social and cultural structure. 5. The quality of interaction between the elder's and caregivers is another factor of the elder's choice of preserving strategy. 5. Preserving dignity in social care differs from preserving dignity in health care, in particular comparing to institutional care.

Table 3.2 Extraction data of supplementary studies

Author/ Country	Participants		Research Design	Key Findings
	Size	Characteristics		
Holmberg et al. (2012). Sweden	21	1. 11 female, 10 male. 2. Age range: between 52 and 99 years old. 3. Durations of home: 10 under one year, 10 between 1 to 2 years, and one over 8 years.	Qualitative; interview	1.Three themes: (i)To be a person: have right to make choice; to participate in fellowship. (ii) To maintain self-esteem: have control (iii) To have trust: continuity and trust in the nurses' skills. 2 The duality of participants' perception of home care: (i) feel could maintain dignity and self-determination as in their own homes. (ii)feel irritating to have to wait for the nurses' visit and to accept calls from nurses they did not know.
Fekonja et al. (2022). Slovenia	19 participants from four nursing homes	1. 12 female, 7 male. 2. Age: over 65 years. 3. The period of living in a nursing home was between 14 months and 37 months.	Qualitative descriptive study; in-depth interview (two times each participant)	1.The main theme: 'Dignity of older people confined to bed'; three secondary subthemes themes: (i) Emotions: anger, sadness, hope, and faith; (ii) Lived experience: disrespect, dehumanization, and live day today; and (iii) Failure to maintain care: autonomy and relationship. 2. Nurses' attitudes and behaviours affect undignified experiences significant, and nursing homes should provide person-centred, and with a great sense of compassion care.

Roos et al. (2022). Sweden	20 participants (eight men and 12 women)	1. 8 male, 12 female. 2. Age: 1 under 80, 18 were between 80 and 94, and 1 over 95 years. 3. Duration of residence: (1) 6 < 12 months, (2)4 between 13 and 24 months, (3) 6 between 25 and 36 months, (4) 1 between 37 and 48 months (5) 3 over 48 months.	Qualitative; individual semi-structured interviews	One overarching theme: wanting to be treated like one still matters. Three categories: 1.to be able to manage daily life: (i)To maintain abilities by being physically and cognitively active; (ii)To feel free. 2. to be supported: (i) To feel encouraged by the staff to maintain one's abilities; (ii) Want the staff to support influence. 3. to have influence, and to belong to a social context: (i) To maintain and create new social relationships; (ii) Want the surroundings to support social relationships
Hasegawa and Ota (2019). Japan	12 residents	1. 3 male, 9 female. 2. Age: 1 under 80 (75 years old), 9 under 90 years, and 2 over 90 years. 3. Duration of residence: from 2 months to 146 months.	Qualitative-hermeneutic phenomenological approach/in-depth interviews and literature review (* Each participant was interviewed at least 2 times.)	Five themes were obtained after combining two types of materials: 1. individual dignity not affected by others; 2. dignified care in a narrow sense; 3. elements of the staff side; 4. dignity in relation to family members, friends, society, and other residents; 5. dignity in relation to nursing care facilities and the nursing care system.
Šaňáková and Čáp (2018). Czech Republic	10 general nurses	1. Age: between 38 and 58 years. 2. Work experience: from 8 years to 35 years. The average was 22.4 years.	Descriptive qualitative study; in-depth interview (field notes as the complement for the process)	Six themes were identified: 1. regarding elderly adults as unique human beings; 2. Privacy and embarrassment;

		3. Institution types: 5 worked in LTC facility, and 5 worked in nursing home.		3. Quality of relationships; 4. communication; 5. Quality of care; 6. Environment.
Robison et al. (2018). Canada	8 older people	1. 7 male, 1 female. 2. Age: 5 between 60 and 64, and 3 over 65 years. 3. Years in assisted living: (1) 3 between 2 and 10 years, (2) 3 between 14 and 25 years, (3) 2 over 25 years.	Qualitative: descriptive phenomenological; semi-structured interview	Five constituents: 1. dignity is an intrinsic or self-regarding experience: related to self-respect, personal value. 2. dignity is an extrinsic and reciprocal experience, and regards others, and is embedded in social relationships: being accepted by others. 3. dignity can be eroded by ageism, stigma, discrimination, and alienation. 4. dignity can be interrupted when positive and negative symptoms of schizophrenia are present ad misunderstood by others. 5. dignity can be enhanced when oneself and others embrace a recovery-focused relationship,
Gallagher et al. (2017). England, UK	1. Action research groups (led by registered nurses): approximately	Care setting: one specialist care home for mental health and dementia care; three general care homes.	Qualitative: action research and interview	1. Both staff and residents indicated that they feel being empowerment and add their self-worth through discussing dignity, and enable the collaboration. 2. This bottom-up approach is helpful to

	6-9 participants in each care home. 2. Residents and relatives group: approximately 2-9 participants in each care home, with an average of 4 members in attendance at each of the six meetings.			improve ethical practice, including dignified service within care homes/residential settings.
Slettebø et al. (2017) / Denmark, Norway and Sweden	28	1. 8 male, 20 female. 2. Age: age range from 62 to 103 years. 3. Location: 5 from Denmark, 15 from Norway, and 8 from Sweden.	Descriptive qualitative; interview	The two categories were found to be fostering dignity: 1. Active participation: participating in meaningful activities; feeling of being seen and heard as a member, and 2. Experiencing individualised activities: related to the feeling of autonomy and have the possibility to choose an activity they enjoyed doing.

Høy et al. (2016)/ Denmark, Norway and Sweden	28 residents from six nursing homes in Scandinavia.	1. 21 female, 7 male. 2. Age: from 62 to 103 years. 3. Duration of living in nursing home: from a few months to 22 years.	Qualitative/ Individual interviews	The meaning of maintaining dignity was constituted in a sense of vulnerability to the self, and elucidated in three major interrelated themes: 1. Being involved as a human: bodily self (i) Related to physical changes which may threat to self-image and self-respect. (ii) Can get help when need 2. Being involved as the person one is and strives to become: personal self (i) related to the declension of capacities and dependency in daily activity. (ii) to express their thoughts whether is need help or reject the arrangement that they do not like. 3. Being involved as an integrated member of the society: social self (i) related to left familiar environment and relationship moved to nursing home (ii) have role in someone's life, participate meaningful activities
Sæteren et al. (2016) / Scandinavia countries	28	1. 8 male, 20 female. 2. Age: age range from 62 to 103 years. 3. Location: 5 from Denmark, 15 from Norway, and 8 from Sweden.	Qualitative; interview	1. participants used different strategies to deal with life in nursing homes. 2. Three themes emerged about the participants trying to preserve dignity through expanding their life space. (i) Striving for being at home: privacy and personal space;

				(ii) Striving for inner freedom and autonomy: routine and residents' experiences of self-wort as well as intrinsic value. (iii)Striving for meaningful life: The connection between present and remembrance.
Walker and Paliadelis (2016) / Australia	18 participants	1. 8 male aged between 77 and 89 years; 10 female aged 79 and 86 years. 2. All participants were physically frail.	Qualitative-phenomenological approach; In-depth interviews	Three major themes which emerged from the analysis are presented here: 1. Loss of autonomy, dignity and control: including privacy-personal space; 2.Valuing important relationships; with significant other and staff; 3.Resigned acceptance: their own situation.
Heggestad et al. (2015)/ Norway	1. Participant observation: 15 residents of two nursing homes--8 from the nursing home 1, and 7 from the nursing home 2) 2. Interview: 7 relatives of residents	1. Age: (1) Nursing home 1 (special care unit): aged 79 to 99 years; (2) Nursing home 2: (general unit): aged 78 to 93 years. (3) Relatives: A. 3 from the special unit, they were 83, 56, and 59 years old separately. B. 4 from the general unit, they were 51, 49, 86, and 64 years old separately. 2. Relation: (1) 2 spouses, (2) 2 daughters (3) 1 daughter-in-law, (4) 1 son, and	Qualitative: phenomenological philosophy rather than the methods; participant observation, interview	1. The most important thing for ensuring patients with dementia live a life in dignity is: (i) take them as equal human beings (respect for their personhood) and (ii)satisfy their relational needs. 2. Care worker's attitude is the key factor, which affect confirming residents as human beings and meeting their relational needs. Time and resources available for communication affect worker's situations too. 3. Person-centred care is the practical method. 4. Promoting identity and self-esteem is the same as promoting the dignity of identity or personal and social dignity. **Overall: care which focuses on the resident's personhood, combined with a relational focus, is of great importance in maintaining the dignity of people with dementia living in nursing homes.**

		(5) 1 niece.		
Heggestad and Slettebø (2015)/ Norway	Participant observation: 15; 5 for interviews	1. All the participants of participants observation have dementia. 2. Three participants' stories were used in the article. Two participants lived in the special unit, and one lived in the general unit.	Qualitative-case study (three cases); participant observation, life story; interview	1. Life storytelling can be seen as an important way of preserving dignity for people with dementia to present and maintain dignity of identity or social dignity. 2. The connection between storytelling and identity: storytelling is related to personal identity because people could demonstrate who he/she is through telling their stories to others. 3. The authors consider that people with dementia could feel more confident. 4. Nurses can enhance those people's dignity by listening to their stories.
Du Toit et al. (2015)/ Southern Africa	15 professionals (6 in group 1; 9 in group 2)	1. Group 1: (1) Age: between 47 and 74 years. (2) Experience in elderly care: from 0.5 year to 22 years. 2. Group 2: (1) Age: between 41 and 75 years. (2) Experience in elderly care: from 3 years to 40 years.	Descriptive qualitative study; nominal group	Three themes were emerged, and each theme has three categories: 1. Helplessness: quality of care, autonomy and choice of residents; access and functional abilities. 2. Loneliness: belonging; co-occupations (and sense of community); Companionship (and/or separation). 3. Boredom: doing; becoming; environmental significance.
Heggestad et al. (2013)/ Norway	5 participants for interview	1. Participant observation: (1)Age: Nursing home 1 (special care unit): aged 79 to 99 years; Nursing home 2 (general unit): aged	Qualitative phenomenological and hermeneutic approach;	Three themes: 1. To be seen and heard: feelings of not being confirmed and respected as individual autonomous persons.

		78 to 93 years. 2. Interview: (1) 4 female, 1 male. (2) 2 from the special unit, 3 from the general unit. (3) age: between 84 and 94 years old.	participant observation and interview.	2. Captivity:lack of freedom 3. Homesickness
Nåden et al (2013)/ Sweden, Danmark, and Norway	28 family caregivers of nursing home residents	1. Age: from 47 years to 89 years. 2. Relation: (1) 7 spouses (6 husbands, 1 wife); (2) 14 daughters; (3) 5 sons/ son-in-law; (4) 1 sister; (5) 1 cousin.	Explorative qualitative research; individual interviews	1. Overall theme: Feelings of being abandoned; 2. Six sub-themes reflect the types of residents would feel abandoned: (i) deprived of the feeling of belonging. (ii) acts of omission; (iii) deprived of confirmation; (iv) physical humiliation; (v) psychological humiliation, (vi) deprived of aspects of life. 3. Subthemes: Freedom, responsibility and a commitment for others are considered as the fundamental dimensions of dignity.
Oosterveld-Vlug et al. (2013)/ Danmark, and Norway	28 professionals	1. 23 female, 5 male. 2. Age: between 25 and 55 years old. 3. Types: 13 physicians, 15 nurses 4. Experience in nursing home care: 5 under five years, 23 over five years.	Qualitative descriptive study; in-depth interview	Four main themes related to residents' dignity: 1. residents' ability to keep tier individuality: functional incapability interweaves with personal traits resulting in someone's level of dignity. 2. Treat others as one would like others to treat oneself: treated residents with respect; 3. General dignity-conserving care for individual nursing home residents; 4. Conflict values with regard to promoting dignity in daily care.

| Zhai and Qiu (2007)/ China | 26 participants | 1.Types: (1) 10 family members, (2) 6 elderly persons, (3) 4 assistant nurses, (4) 3 physicians, and (5) 3 administrators 2. Settings: home-based LTC and institution-based LTC. | Qualitative; interview | 1. Filial piety is still a very strong belief in their mind, so many of participants believe that children have a responsibility to care their elder parents. 2. Most participants agreed that home base care is the better care model for the elderly, but if their care needs become complex, institutional care might be more proper while older people prefer to employ assistant nurses to care they at home. 3. "One couple one child" policy in 1980s will influence the structure and the care ability of family in the coming years, combining with other structural factors and policy result in challenges of long-term care system in China. 4. Most participants believed that older people have the right to make decisions about their life if they are competent. Family members should involve discussing but the last decision still should make by older people. 5. All participant prefer to compulsory individual savings for LTC. 6. All groups suggested the concept of respect as one of the words they used to describe dignity, for example, respect their choices about their life affairs. Some participants also mentioned autonomy and self-determination |

3.2.1 Summary of the extraction data

This research aims to explore the service users' dignity in LTC, mainly those who use non-residential care. People use LTC services at home, including home-based care (except palliative care) and other non-residential care. The following section is derived from the extract of the inclusion studies, and the information on the supplementary research will be added in this section for comparison in methodology primarily.

Two inclusion studies were conducted in Scandinavian countries (Sweden and Norway), and one was in Portugal. In the supplementary information, nine pieces of research related to Scandinavian countries: two studies from Sweden, three from Norway and five were cross-country studies that included Demark, Norway and Sweden. The rest of studies are one each from Australia, Canada, China, Czech Republic, Japan, Slovenia, Southern Africa and the United Kingdom.

Generally, of the 21 studies, four focus on dignity in home-based care services, and the number of residential studies is more than four times that of the studies on non-residential care services (17 studies). This gap reflects the deficiency of home care in research related to dignity in the LTC system, which is essential for supporting people ageing at home for as long as possible integrity.

3.2.2 Summaries of Results

Besides the fundamental information about countries and care settings, the methodology summary would provide more aspects for understanding, including the data collection method, analysis approach, and the feature of the selection of participants.

Methodology

Three inclusion studies are qualitative research and the extra studies because one of the exclusions is quantitative research. As mentioned in the introduction, this study aimed to understand better the elderly LTC users' experiences and interpretations of their dignity when using services. According to Creswell and Poth (2017), a qualitative approach is more suitable for capturing personal experience than a quantitative one.

Moreover, some studies mentioned phenomenological approaches owing to the emphasis on exploring people's experiences. One from the selected studies (Kaldestad and Nåden, 2022) and 11 from the supplementary ones, including the two basic types of phenomenological philosophy: six related to the descriptive approach that emphasises the content of personal experiences, and how the phenomenon was experienced rather than interpreting those experiences (Doyle et al., 2020; Sloan and Bowe, 2014); seven mentioned the hermeneutic approach that considered and interpreted the relationship between people's existence and the phenomenon and the world rather than describing the phenomenon (Sloan and Bowe, 2014).

Research Aims

The research aims of the selected research are similar but with slight differences. One of the included studies focused on the older service users' understanding of dignity: 'to deepen the understanding of the meaning of dignity' (Kaldestad and Nåden, 2022, p. 1), and another concerned about the notion of dignified care with the description of 'to explore and analyse how good and dignified care is perceived and expressed' (Andersson and Sjölund, 2022), and the other, José (2016) explored undignified experiences and the participants' strategies for responding to those negative experiences.

The other studies shared similar aims of exploring or describing the participants' experiences or interpretations whether the care setting is private houses or institutions.

The only home-based care research in supplementary studies aimed to describe users' experiences and perceptions of receiving nursing care at home (Holmberg et al., 2012). Most of the residential care studies focused on how to preserve dignity when encountering undignified situations (Roos et al., 2022; Sæteren et al.2016) and the meanings of the experiences for older people (Robison et al., 2018), or further, the strategies for overcoming or adjusting to their interpretations (Fekonja et al., 2022). On the contrary, how to realize 'dignified care' and the potential influencing factors were the focus of Gallagher and colleagues' (2017) research. They intended to identify a method for translating dignity from an idea into care home practice. Moreover, like the theoretical research, Hasegawa and Ota (2019) aimed "to characterize the concept of dignity in care for elderly subjects in residential facilities" (p.1).

Generally, these aims connect to personal experiences or interpretations about dignity fundamentally and extend the concerns to different dimensions, like the strategies against undignified situations, the definition or elements of dignified care, or the meaning of dignity itself in residential care services. In order to obtain relevant information for reaching these aims, these researchers selected several approaches for collecting data.

Data Collection and participants

This section includes the method of data collection and the sources of data. These studies share similar aims in terms of exploring older people's dignity in the LTC system; however, older people's ideas are not the only sources of information, families and relevant professionals also provide various viewpoints.

All the researchers of the selected studies conducted in-depth interviews to collect the data; however, the interviewees were different. Three types of people who may involve in a LTC service are the participants in these studies, including older adults (service users), users' family members, and professionals involved in LTC services (nurses, care workers, physicians and managers). Andersson and Sjölund (2022) interviewed the managers and care workers to collect information about dignified care and the difficulties of providing night care service, while Kaldestad and Nåden (2022) invited older service users to share their experiences when using LTC services at home. José (2016) used participant observation and informal conversations with people involved in the participants' care services, including older people and care workers. In some cases, the researcher would also have conversations with the older users' relatives.

In supplementary studies' situation, most studies used in-depth interviews as the primary means to collect data, except Du Toit et al. (2015) conducted the nominal group interview. Moreover, several studies combined other methods to gain more information, like participant observation (Heggestad and Slettebø, 2015; Heggestad et al.,2015) and systematic literature review (Hasegawa and Ota, 2019). Gallagher and colleagues' (2017) research provided another example, and they employed the action research approach to identify a method for translating dignity from an idea into care home practice and interviewed the participants' feelings in the process.

Regarding the sources of data of supplementary studies, most studies have sole data sources, and older people are the primary participants according to the research aims of exploring service users' experiences. Nine studies only have older service users as participants, while four studies focused on the professionals' perspectives about older people's dignity in the LTC services (Andersson and Sjölund, 2022; Šaňáková and Čáp, 2018; Du Toit

et al., 2015; Oosterveld-Vlug et al., 2013b), and two paper provides the family members' opinions about the dignity of their aged relatives who live in nursing homes (Heggestad et al., 2015; Nåden et al., 2013). Moreover, mixed sources in three studies provided different perspectives for increasing the variety of data (Gallagher et al., 2017; José, 2016; Zhai and Qiu, 2007).

Generally, a qualitative approach was appropriate regarding those studies' research questions and aims, and the in-depth interview was also proper method for data collection. According to Carter et al. (2014), individual interviews are the ideal data collection method if the aim is to obtain information about personal experiences, which may explain why all the studies adopted an in-depth interview approach whether as the primary means or the auxiliary method.

3.3   Quality Appraisal

In the protocol of systematic review, critical appraisal is one of the essential parts of this approach to ensure the reliability of the evidence for decision-making in healthcare, where decisions could affect people's health and lives (CRD, 2009). Several fundamental questions need to be answered when evaluating the quality of the selected studies, including methodology, sampling, data collection, data analysis, ethical considerations, and research findings (Gough et al., 2017). However, before the above questions, when to conduct the appraisal and how to use the results should be considered before evaluating the dimensions mentioned previously.

Some researchers may conduct the appraisal before or after data extraction, depending on their intention of using the assessment results, because there is a flexible principle of timing when conducting the assessment and how to use the appraisal results (Boland et al., 2017). Some researchers may

employ the assessment results as an indicator to decide to keep or exclude a selected study before analysing because they consider the possible adverse effects on choosing the appropriate intervention or policy measure if a selected research's quality was flawed (Greenhalgh & Brown, 2017); some may keep all the included studies whatever the appraisal result would be.

This systematic review aims to focus on older adults' experiences in the field with deficient information rather than making a treatment decision, and this systematic review's fundamental concern is obtaining as broad information as possible. Therefore, the author has the perspective of keeping all the included studies even if they may have some flaws in quality.

Two appraisal tools were mentioned in Chapter 2 (2.6) for different types of research: CASP for qualitative research and MMAT for mixed methods research. However, according to the selection results, all the selected and supplementary studies are qualitative research. Regarding the questions, CASP emphasises the connection between research aims and methodology, and the focus of MATT is research questions and methodology. Moreover, CASP includes the criteria for recruitment, the relationship between the researcher and participants and ethical issues not mentioned in MMAT.

Considering the slight differences between the two tools, the assessment tool in this review refers to CASP and the quality criteria for qualitative research in MMAT for comprehensive appraisals. Assessments were conducted after the data extraction process, and the results are shown in Table 3.3 (the result of CASP) and Table 3.4 (the result of MMAT). Moreover, for complementary, the supplementary studies would be evaluated by CASP, and the results are in Appendix 3.

The responses were recorded as 'yes', 'no', or 'can't tell' for each question. The CASP instructions provide some hints of the crucial points for

researchers to consider how to facilitate each assessment. However, compared to the four-level result (High, Moderate, Low and Very low) in GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) (BMJ, 2023), the 'can't tell' option seems vague. MATT has the same responses for the quality criteria, and its instructions for the 'can't tell' response indicate that there is no appropriate information to answer 'yes' or 'no' or that the information is unclear (Hong et al., 2018). Therefore, when evaluating, the author referred to its explanation of 'can't tell'.

In the supplementary studies, a few reports were marked 'can't tell' or 'no' in several aspects. These aspects concentrated on the research aims, recruitment details, ethical considerations and the relationship between the researcher and participants. Regarding the recruitment strategy, for example, some studies were marked 'can't tell' on the question related to sampling because the recruitment details were blurred in the research. As the description reads, 'ten residents in care homes were invited to participate in the research', omitting information related to the recruitment criteria of participants and the types of care facilities or inviting nursing home administrators who are not directly involved in LTC service delivery but without explanation of the reason for their inclusion.

In summary, vague descriptions will result in 'can't tell', and a lack of information is connected to the result of 'no' like one study omitted ethical discussion was the reason for being marked 'no'.

Table 3.3 Appraisal Results by CASP

Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Note
Andersson & Sjölund, (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Without information for assessing Q6.
Kaldestad & Nåden (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
José (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	

Note. 1. Question 6: Has the relationship between researcher and participants been adequately considered?

2. The 10th question of CASP is related to the value of the research was not included in.

Table 3.4 Appraisal Results of MMAT

Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Note
Andersson & Sjölund, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Kaldestad & Nåden (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
José (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	

3.4 Thematic Analysis

As mentioned in Chapter 2 (2.7), a three-stage approach will be adopted for thematic analysis. According to Thomas and Harden (2008), the three stages include free coding through reading findings line by line, organising these 'free codes' to construct descriptive themes, and developing analytical themes.

<u>Coding and developing descriptive themes</u>

The materials for analysis focus on the findings of a study, although the titles and content may differ from each paper, including the parts titled 'findings', 'analysis', 'results', or 'conclusions' in general. This process would be conducted with all three included studies, and the data of supplementary studies might be used for discussion but not included in the coding and analysis process.

After reading the context, the author selected and coded text segments like 'Good and dignified care was also expressed as striving to give something extra' and 'Dignity is about having self-determination, it was so important in the first step' (Andersson and Sjölund, 2022). Table 3.5 demonstrates some examples of this step. The text could be the participants' words that were cited in the report or the analysis of the researcher in the findings of the selected study.

Regarding the results of the free coding, the author organised these codes into descriptive themes in the second step. The author reviewed and categorised all the codes into descriptive themes in this stage. For example, the code 'She needed to be taken care of, but the nurse followed the rules that she had learned; washing does not belong to the evening shift' (Kaldestad & Nåden, 2022) was organised into the descriptive theme of 'rules are prior than their needs' and 'feelings of being ignored'. Six

descriptive themes emerged at the end of the second stage and formed a synthesis of the findings of included studies according to the six themes.

Table 3.5 Example of Free Coding

Text segments
"For me, personally, dignity is that you have influence and participation. That one may retain one's personal integrity." (Andersson and Sjölund, 2022)– citation of participants' interview in the research. "According to the care workers, learning about every recipient's needs and preferences was important for dignified care" (Andersson and Sjölund, 2022)- the researchers' analysis.
"She was dissatisfied with not being able to maintain the rhythm she previously had." (Kaldestad and Nåden, 2022) "Non-confirming encounters has much to do with not being seen or being allowed to be the unique person the human being is." (Kaldestad and Nåden, 2022)

In the final stage, the analytical themes would be produced referring to the synthesis of the findings of the included studies. The synthesis seems to answer the research question of exploring older users' dignity experiences in home-based LTC services through different dimensions: personal, interpersonal, and social. However, one common analytical theme, the dignity of identity, emerged after further reviewing this synthesis and the findings of the selected studies and considerations. In other words, descriptions of older people's dignity experiences in different dimensions reflected this joint concept.

The following section will demonstrate the theme, dignity of identity, demonstrating factors of the dignity of the identity of the three dimensions mentioned above. Notably, it does not mean that these concepts are in a hierarchical relationship. The reason for adding the three dimensions is to demonstrate the factors in different dimensions toward older people's dignity of identity according to the selected studies.

3.4.1 Dignity of identity

From the aged service users' experiences, the feeling of not being the previous self is the typical emotional reaction when they are aware of losing activities, losing social contacts, losing privacy, losing power and respect from others (Kaldestad and Nåden, 2022; José, 2016). Those losses were mentioned in all included studies with older people's perspectives, except the research interviewed managers and care workers.

According to the thematic analysis, multiple losses resulted in older people losing the dignity of identity. The loss of health or body function and the consequent effects in daily life erode the sources of older people's self-esteem, for example, losing the ability to care for themselves. Some participants describe themselves as a burden for their family caregivers. They used descriptions such as, 'Now I have no value at all, and I once had so much value' (José, 2016), and they coped with feelings 'without being seen or being allowed to be the unique person the human being is' (Kaldestad and Nåden, 2022).

Furthermore, those losses lead older people to build a caring relationship with their caregivers, whether the family caregivers or relevant professionals, and caregivers or significant persons become a crucial part of an older person's daily life, significantly influencing their interpretation of themselves. Last is the broadest dimension related to the society where older people live. Social values shape people's perceptions of ageing, independence, personal responsibility and others, which affect the viewpoints of older people to review their situations when they encounter changes in later life and the interpretation of dignity (José, 2016).

Besides, the supplementary studies provided different perspectives from the significant persons and practice workers in different care settings. For example, the family caregivers in Nåden and colleagues' (2013) research

mentioned that deprivation of confirmation of patients' existences results in older residents' undignified experiences. In other words, some workers might neglect the resident's situation when they need help. Oosterveld-Vlug et al. (2013) provide care workers', nurses' and physicians' viewpoints about older residents' dignity in nursing homes.

Despite the findings derived from the data of different roles in LTC services, and those elements could be various, they shared the feature related to a person's self-identity. For example, some home care users require personal space to shelter themselves from the indignity situation (José, 2016), while the residents in nursing homes ask for personal space for privacy (e.g. to prevent being exposed in front of other residents unexpectedly, Šaňáková and Čáp, 2018). Although those needs have different purposes, both are related to preserving a person's self-esteem. Moreover, many studies also identified the connections between dignity and personal identity in indirect descriptions. Most of them were the elements that affect individual feelings of dignity, for example, being seen and heard as a person, maintaining the family role in the past and self-determination (Kaldestad and Nåden, 2022; José, 2016; Heggestad et al., 2013).

The lack of fundamental components of personal dignity would lead to undignified feelings and vice versa, whether the sense of absence of those elements was from an individual's self-perceptions or from their interaction with other people. As Nordenfelt (2004) mentioned, elements of identity related to the integrity of the subject's body and mind are sometimes dependent on a person's self-image; in other words, the factors that affect self-image simultaneously influence personal dignity. Moreover, elements affecting the dignity of identity could be extracted from situations affecting older service users. Those situations relate three dimensions in people's daily lives: personal, interactional, and social aspects. These three dimensions correspond to three subthemes.

3.4.2 Personal Dimension- Self-esteem

Situations affecting older people's experiences of dignity may overlap across different dimensions, and those that make older people feel a loss of self-esteem may relate to both personal and interpersonal dimensions.

In the personal dimension, their frustrations at losing respect, autonomy, decision-making, choice, and privacy in daily lives were mentioned frequently in their accounts of their undignified experiences (Kaldestad and Nåden, 2022; José, 2016; Holmberg et al., 2012). The most significant examples were 'treated with respect', 'have privacy', 'can make choices', and 'have control over their lifestyles'.

In residential care studies, various elements were related to personal concerns when receiving LTC services, reflecting the shared consequences of the damage to self-esteem and personal dignity (Fekonja et al., 2022; Roos et al., 2022; Robison et al., 2018). For example, the loss of the ability to control their lives could lead to feelings of uselessness, or the loss of privacy made them feel they were not seen as individuals. These feelings could impair older people's self-esteem, and their dignity would decline simultaneously. Therefore, self-esteem was a reflection of the personal dimension of the element of dignity of identity (Holmberg et al., 2012).

Conversely, although the damage to self-esteem resulted in indignity for older people, their dignity could be improved by remedying the damage to their self-esteem. In their studies, Høy et al. (2016) and Sæteren et al. (2016) provided evidence that some older people strive to develop strategies to preserve or obtain their dignity after undignified experiences. For example, when older people have to move into a nursing home, they tried to accept it by decorating their own rooms similar to the former house even they could not change the decision that made by others.

3.4.3 Interaction dimension: Relationships

Suppose the previous paragraph is about an individual's perception of personal situations. In that case, this section relates to the perception of relationships with older service users, including family members and caregivers. For the people who receive LTC services at home, the most important relationship is that with the family caregiver.

The participants in José's (2016) research were typical examples. Older people feel they are losing dignity when their caregiver ignores them; therefore, maintaining a good relationship with the primary caregiver was one of the strategies to preserve dignity for some older people. Moreover, not only family caregivers but also friends, relatives, and care workers are the crucial parties in older people's interaction with others. Andersson and Sjölund (2022) demonstrated the perspective of care workers, who also agreed that positive relationships with care recipients is one of the elements of dignified care.

In a residential care setting, relationships with care workers and other residents become the most important elements (Roos et al., 2022; Hesagawa and Ota, 2019). Relationships between older users and those involved in care service affected dignity of identity through interactions with other people. The findings demonstrated some elements that could affect the relationships and an individual's dignity experience.

Descriptions such as 'being seen and understood', 'being treated with respect', or 'respect their personhood' were some examples of the participants' concerns, and they would experience indignity if those needs were not met when using LTC services (Kadlestad and Nåden, 2022; Heggestad et al., 2015a; Woolhead et al. 2006; Bayer et al., 2005).

Participants had different concerns about the relationships between different persons, but their expectations were similar; Šaňáková and Čáp's (2018) findings may provide a simple but precise point in terms of the quality of relationships.

The relationship between this theme and dignity of identity was affected by the results of the interactions with other people, and their dignity was affected significantly by other people's attitudes or gestures in the communication process (Høy et al., 2016; Holmerg et al., 2012). Therefore, communication skills play a crucial element in the quality of relationships, which care workers acknowledged, whether the care setting was users' homes or care facilities (Andersson and Sjölund, 2022; Hesggetad et al., 2015;) and older people (Fekonja et al., 2022; Woolhead et al., 2004).

Therefore, on an interpersonal level, relationships were the key factor in older people's dignity experiences, and the communication skills and attitudes of workers were an essential element in improving users' dignity. In summary, a supportive relationship, good communication, and respectful treatment were shown to improve older people's dignity.

3.4.4 Social dimension: Social Values

Social values seem to be slightly distant from the previous dimension, but, whether the subjective perception of older people themselves or the attitude of other people towards the elderly, social values implicitly play an influential role. The most significant example is that older people feel themselves to be a burden on their family and society when they experience a loss of activities (José, 2016) while society admires independence.

Values are rooted in people's mind and affect their judgements of themselves and other people. Although this dimension was not mentioned directly in the included studies, the situations of older people's lives implied the influence of social values. Self-judgement was one example, and attitudes towards older people constituted

another. Moreover, attitudes towards ageing or the older generation of the public affect older users' dignity.

Differing from the previous factors that affect older people's dignity of identity in LTC services directly, the effect on personal dignity of social values was relatively more indirect than that on the changes of bodily function of older service users or disrespectful behaviours towards them.

Combining the findings of the included and residential studies, José (2016) indicated that the micro factor and the social discourse on ageing (macro factors) affect people's struggle to preserve their dignity, particularly to stereotypes of older people or age-related stigma or ageism. Andersson and Sjölund (2022) provided another finding about the policy. Although a new policy with goals of dignity has been developed, the lack of guidance and resources still makes dignified care unrealistic in practice. Besides the included and supplementary studies, Woolhead et al. (2006) and Calnan et al. (2006) also reflected on the social system-level difficulties in improving older people's dignity in care services, concluding that the lack of time, lack of staff, and lack of resources were factors in the failure to preserve aged users' dignity in the care process.

Those findings show that the social value affecting older people's dignity could occur on two levels. On the micro level, how society values the older generations affects the attitude of people, not only the public but also the older people themselves. As mentioned in previous paragraphs, the worry or the fact of losing functions along with ageing and becoming dependent decreases older people's dignity. In addition, the way in which people view ageing influences their interactions with older people, whether in a care relationship or not. Conversely, the policy of dignity goals reflects the social value of emphasising older people's dignity, although the findings also indicated that more tremendous efforts and more concern about how to realise those goals in practice are needed.

Generally, the three subthemes that affect the dignity of identity overlap because an individual lives in society and society consists of people.

Chapter 4 Discussions and Conclusion

In Chapter 1, a definition of dignity floats from the international conventions and national political documents, which refer to the inherent dignity of all human beings and are connected to human rights. The range of discussion concentrated from all humanity to an individual, but the vagueness remains the same.

This systematic review aims to identify the situation related to older people's dignity, particularly those who use LTC services at home.
Some directions for improving dignity through LTC services emerged after identifying the situation of older people who receive service at home. Through the review and synthesis of the findings of the included studies, the dignity of identity was generated through a thematic analysis, which reflects the most threatened dignity of older people in the LTC system. Moreover, the three subthemes explain the factors of the changes in personal dignity in different dimensions.

A similar result of residential care studies also identified from the interviews of the residents that the dignity of identity also plays a crucial role in the interpretations of older people in residential care settings (Heggestad et al.,2015). However, it does not mean that it reflects the same unfavourable situations.

Privacy could be an example. Both users and residents mentioned privacy when talking about the decline of self-esteem and the undignified feeling. Older people in opposite care settings may refer to different situations. In home-based care situations, privacy refers to the space for a specific person who should not step in without allowance, whether it is the house or a room (Kaldestad and Nåden, 2022; José, 2016; Holmberg et al., 2012), while privacy to older people in nursing homes also means not to be exposed in public areas (Šaňáková and Čáp, 2018). Furthermore,

Furthermore, compared to the findings from the included studies and the residential care studies, for older people who receive home care, personal factors might be the primary reasons for their undignified feelings, like being worthless or not having value anymore. On the other hand, the primary source of indignity of the aged residents might be the interactions with others due to the feelings of "not being treated with respect".

Therefore, the similarity of the interpretations of dignity between residential care and home care may raise the question of how people preserve dignity through LTC services. When ageing in place, it seems not to be a panacea.

4.1 More Considerations: uneven development

Usually, the research method is properly connected to the research questions, but two phenomena may need consideration. The first is the concentration of studies on residential care. The ratio of home-based care to residential care was four to nineteen when excluding six pieces of research with mixed-care settings. However, according to an investigation into the arrangements of older people, the majority of members of the elderly generation live at home in later life rather than in residential facilities (Morley, 2012; UN, 2021).

In other words, most older people receive LTC services at home before moving to facilities for intensive care. This current research trend reflects the possibility of gaining a decent understanding of the major group, which consists of the primary users of LTC services, especially home care services. Thus, increasing the understanding of their experiences of dignity would be a critical factor for improving older people's dignity in LTC care services.

Moreover, from an international perspective, a country bias was noticeable. The concept of dignity is connected to the development of modern Western philosophical and political thoughts (Rosen, 2012); therefore, most

research on dignity issues in LTC has been conducted in Western societies, where the foundation of this value was built.

Furthermore, the findings of this review indicated that the studies on dignity in Western countries seem to have reached a degree of data saturation. Different studies have repeatedly mentioned similar values and explanations, such as independence, autonomy, respect, choice, or decision making. On the one hand, these studies enrich the understanding of dignity – the history, the development, and the transition over time – and this will be a consistent concern in Western societies since it is a fundamental value. Therefore, its development in this area is foreseeable. On the other hand, this trend increases the possibilities of understanding dignity in different social contexts.

However, dignity has been incorporated into policies in more and more non-Western societies along with the spread of human rights (Shulztiner and Carmi, 2014). For example, the concept of dignity can be found in the long-term care policies of Japan and Taiwan (Japan Law Translations, 2007; MOHW, 2007, 2016). In other words, the lack of understanding of dignity in different cultures is still a gap that needs to be considered.

4.2 Limitations and Risk of Bias

Some limitations or situations of this research appeared in the process and could be improved in future research.

4.2.1 Limitations

Most selected and supplementary studies were conducted in primarily English-speaking countries, or at least the reports were published in English. The language limitation reduced the opportunity to access the studies conducted in different countries or published in other languages (e.g. German, French, and Czech). In particular, the countries had also implemented LTC for older people. Moreover, some researchers may only publish their studies in domestic academic journals.

Therefore, the language limitation could reduce the opportunities to consult a broader range of literature. Therefore, three Taiwanese databases were included with the intention of increasing the variety of literature consulted, although all the potential Taiwanese literature was excluded in accordance with the criteria.

Moreover, in the process of selecting studies, the guidance on systematic reviews (CRD, 2009) usually advises establishing a review team and an advisory group to resolve and discuss uncertain situations, such as the selection of studies for which it was difficult to make an inclusive or exclusive decision. This ideal design is challenging to realise for a master's student. Dundar and Fleeman (2017) provided some compromise methods, such as discussions with the student's supervisor, peers, or friends or the sole researcher performing the review again a few days or a week after the first selection. The current research adopted the last method due to the time limitation. The author conducted the second review for selection a week after the first selection.

4.2.2 Risk of Bias

Some confusion occurred in the screening literature related to the criteria. One included criteria is older people who use LTC services at home. According to the general usage, the definition of older people could be "people aged 60 years or over" (e.g. UN, 2017) or people aged 65 years or over (WHO, 2015). Considering a broader range of literature, this research adopted 60 years old or over as the definition of older people. However, one study was excluded because it had participants under 60, although it reached almost all inclusion criteria.

Similarly, some studies on residential care have included participants without providing details about their age. These studies were excluded from the selected literature list because the young participants did not meet the age criterion. However, it might be a risk that Boland et al. (2017) suggested related to missing valuable data. Therefore, the author kept it as supplementary data.

4.3 Future Research

Therefore, the findings show that the method of data collection, the care setting, and the uneven development of research on dignity are all noticeable aspects of current studies and possible avenues for future research.

Most selected and supplementary studies were conducted primarily. First, according to the analysis, the same factor that affects the dignity of identity might be mentioned in different care settings but could reflect the different needs of older people. For example, interaction between older people and caregivers is crucial in a caring relationship, whether older people live at home or in institutions. However, to improve the caring relationships in different care settings, more details for improving older users' dignity in various care settings. In other words, research on the complicity of caring relationships in different care settings needs more exploration for providing appropriate support to caregivers.

Second, there is a need to expand the perspectives on dignity in care beyond nursing. While there is a wealth of research on dignity from a nursing perspective, other professionals' viewpoints are often grouped together under the umbrella of "personnel/professionals". Exploring various perspectives, including those from different countries and cultures, would help to improve the understanding of dignity.

Third, research on LTC users receiving care at home is still relatively lacking compared with research on nursing home users. Since home care and residential care have different privacy concerns and other issues, identifying the unique needs of users in different dwellings is necessary to improve their dignity and the quality of LTC. Furthermore, in the personal dimension, the review findings suggest that older adults who receive home care and residential care services share common concerns and face similar challenges related to personal dignity and relationships with others. However, there are also differences between the two groups. For instance, those who live with family members tend to emphasise the importance

of their relationship with their loved ones, while those living in facilities are more likely to report undignified experiences related to privacy or personal space.

Forth, there is a need to study the dignity of caregivers and workers. As the findings indicated, the relationship with others is a crucial factor affecting older people's dignified or undignified experiences and the quality of care. Moreover, before being caregivers, they are human beings. Their dignity should be a concern in their studies with the aim of improving people's dignity as it affects the continuity and quality of care. Conversely, understanding the caregivers' dignity in the LTC system would be beneficial to the knowledge of dignity.

Finally, it is essential to consider other types of LTC service users beyond the elderly population. Policies aim to care for all people with LTC needs, and understanding the differences between user groups would expand our understanding of the concept of dignity.

4.4 Conclusion

This systematic review aims to identify the situation related to the dignity of older people, particularly those who use LTC services at home. Four studies were included for the further analysis to highlight older people's dignity experiences.

By synthesising the findings of the included research, dignity of identity emerged to present the various situations related to home care recipients. Moreover, three dimensions of situations presented examples in older people's daily lives. In other words, dignity of identity is affected in situations related to self-esteem, relationships, and social values. These themes were generated from the interpretations of home care setting users.

Therefore, after this review, besides the working definition of dignity mentioned in Chapter 1, the meaning of dignity to an individual, generated from the findings of the included studies, involves affirming their being, self-worth, and self-esteem and being treated equally and with respect when interacting with others and the world in which they live.

To improve the quality of care and promote the dignity of older adults receiving LTC services, it is essential to respond to the multidimensional nature of dignity

and expand the focus to the social dimension, to develop strategies to address ageism, and to establish a society of mutual respect to improve comprehensively the dignity of older people as well that of other groups.

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Appendix 1   Examples of search strategy:

Social Policy and Practice (SPP): abstract, limited in 2000-current

Set	Search Statement
8	((dignity or dignified) and (elder*or frail* or senior* or ag* or geriatric or "older people" or "older adult" or dementia) and ("social care" or "nursing home" or "residential care" or "supported living" or "home care" or "domiciliary care" or "community care")).af.
7	2 and 4 and 6
6	limit 5 to (abstracts and yr="2000 -Current")
5	"social care" or "nursing home" or "residential care" or "supported living" or "home care" or "domiciliary care" or "community care"
4	limit 3 to (abstracts and yr="2000 -Current")
3	elder*or frail* or senior* or ag* or geriatric or "older people" or "older adult" or dementia
2	limit 1 to (abstracts and yr="2000 -Current")
1	dignity or dignified

Scopus: title, abstract and keywords, 2000 to current, English

```
( TITLE-ABS-KEY ( dignity  OR  dignified )  AND  TITLE-ABS-KEY
( elder*  OR  frail*  OR  senior*  OR  ag*  OR  geriatric  OR  "older
people"  OR  "older adult"  OR  dementia )  AND  TITLE-ABS-KEY ( "social
care"  OR  "nursing home"  OR  "residential care"  OR  "supported
living"  OR  "home care"  OR  "domiciliary care"  OR  "community
care" ) )  AND  ( LIMIT-TO ( PUBYEAR ,  2023 )  OR  LIMIT-TO
( PUBYEAR ,  2022 )  OR  LIMIT-TO ( PUBYEAR ,  2021 )  OR  LIMIT-TO
( PUBYEAR ,  2020 )  OR  LIMIT-TO ( PUBYEAR ,  2019 )  OR  LIMIT-TO
( PUBYEAR ,  2018 )  OR  LIMIT-TO ( PUBYEAR ,  2017 )  OR  LIMIT-TO
( PUBYEAR ,  2016 )  OR  LIMIT-TO ( PUBYEAR ,  2015 )  OR  LIMIT-TO
( PUBYEAR ,  2014 )  OR  LIMIT-TO ( PUBYEAR ,  2013 )  OR  LIMIT-TO
( PUBYEAR ,  2012 )  OR  LIMIT-TO ( PUBYEAR ,  2011 )  OR  LIMIT-TO
( PUBYEAR ,  2010 )  OR  LIMIT-TO ( PUBYEAR ,  2009 )  OR  LIMIT-TO
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( PUBYEAR ,  2004 )  OR  LIMIT-TO ( PUBYEAR ,  2003 )  OR  LIMIT-TO
( PUBYEAR ,  2002 )  OR  LIMIT-TO ( PUBYEAR ,  2001 )  OR  LIMIT-TO
( PUBYEAR ,  2000 ) )  AND  ( LIMIT-TO ( LANGUAGE ,  "English" ) )
```

ASSIA: abstract, English or Chinese, Peer reviewed, 2000-current

abstract(dignity OR dignified) AND abstract(elder*or frail* OR senior* OR ag* OR geriatric OR "older people" OR "older adult" OR dementia) AND abstract("social care" OR "nursing home" OR "residential care" OR "supported living" OR "home care" OR "domiciliary care" OR "community care") AND la.exact("English" OR "Chinese") AND PEER(yes)

Airiti Library: articles/keywords/abstracts, Traditional Chinese and English, 2000 to 2023

(尊嚴 OR 有尊嚴的) = Articles/Keywords/Abstracts AND (老人 OR 長輩 OR 長者) = Articles/Keywords/Abstracts AND (長期照照顧 OR 長期照護 OR 長照) = Articles/Keywords/Abstracts

Taiwan Citation Index-Humanities and Social Science (TCIHSS)

("老人".ab or "長輩".ab or "長者".ab and ((stype="*")))/sysbc="2000-2023"//es0
("尊嚴".ab or "有尊嚴的".ab and ((stype="*")))/sysbc="2000-2023"//es0
("長期照顧".ab or "長期照護".ab or "長照".ab and ((stype="*")))/sysbc="2000-2023"//es0
(#1) and (#2) and (#3)

TPL

(尊嚴 =Abstracts OR 有尊嚴的= Abstracts AND 長期照顧 = Abstracts OR 長期照護 = Abstracts OR 長照=Abstracts AND 老人=All fields) And 老人= Abstracts

Appendix 2   Appraisal Checklist

CASP

Questions	Responses		
	Yes	No	Can't Tell
1. Was there a clear statement of the aims of the research?			
2. Is a qualitative methodology appropriate?			
3. Was the research design appropriate to address the aims of research?			
4. Was the recruitment strategy appropriate to the aims of the research?			
5. Was the data collected in a way that addressed the research issues?			
6. Has the relationship between researcher and participants been adequately considered?			
7. Have ethical issues been taken into consideration?			
8. Was the data analysis sufficiently rigorous?			
9. Is there a clear statement of findings?			

MMAT

Questions	Responses		
	Yes	No	Can't Tell
1. Are there clear research questions?			
2. Do the collected data allow to address the research questions?			
3. Is the qualitative approach appropriate to answer the research question?			
4. Are the qualitative data collection methods adequate to address the research question?			
5. Are the findings adequately derived from the data?			
6. Is the interpretation of results sufficiently substantiated by data?			
7. Is there coherence between qualitative data sources, collection, analysis, and interpretation?			

Appendix 3 Appraisal Results of Supplementary Studies

Author	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Note
Holmberg et al. (2012).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Fekonja et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Roos et al. (2022).	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	The detail of selecting RCFs was not clear.
Hasegawa & Ota (2019).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Šaňáková, Šárka & Čáp (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Robison et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Gallagher et al. (2017)	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes	1. The connection between the research question1 and the tool used in data collection (the toolkit) was not clear. 2. The reasons for recruiting residents or family members were not clear.
Slettebø et al. (2017)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	The information about selecting individual participants was not clear.

Høy et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Sateren et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Walker & Paliadelis (2016)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	The information for evaluating Q 6 is not clear.
Heggestad et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Heggestad & Slettebø (2015)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	1. The details of selecting participants for the interview are not clear. 2. The reason for selecting three life stories from five interviews is not clear.
Du Toit et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	The information of ethics issues was deficient.
Heggestad et al. (2013)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	
Nåden et al (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Oosterveld-Vlug et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Zhai & Qiu (2007)	Can't tell	Yes	Yes	No	Yes	Can't tell	Yes	No	Yes	1. Information about research aims is not clear.

										2. Without details of sampling.
										3. The reason for including administrators who do not provide care services was not clear.
										4. Information about Q6 is not clear.
										5. Without information about ethical issues.