Service users' and providers' experiences of equipment provision in occupational therapy; a qualitative study.

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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#### Abstract

#### Introduction

This primary research project applied the principles of Interpretative Phenomenological Analysis to explore occupational therapy practice and equipment for activities of daily living from the perspective of the service users and providers. It concentrated on the geographical area of one NHS Foundation Trust in the United Kingdom.

#### Method

An in-depth review of the literature assisted with the development of the main research project. Nine clinical leaders, 10 occupational therapists, and seven service users participated in face to face interviews. The interviews were analysed ideographically before group level analysis. Interpretation of the data and developing themes were viewed through a clinically based occupational therapy lens. Where possible, links to the wider literature are made within the discussion chapter.

#### Findings

Within and across the three patient sub-groups (clinical leaders, occupational therapists and service users) a common link was identified; that of identity. The super-ordinate themes and sub-themes highlighted the concept of personal and professional identify being affected by the occupational therapists role and ADL equipment. A range of other issues and concerns relating to clinical practice and processes were identified. The overall findings highlighted a range of implications to practice and the need for future research in the area of ADL equipment and occupational therapy practice.

#### Recommendations

A number of recommendations for future primary and secondary research resulted from this research. This includes: a systematic approach to reviewing the national and international literature, extending research to include occupational therapy support staff/other professions and service users, and a closer examination of equipment based outcome measures. Raising awareness of the global impact of ADL equipment within occupational therapy practice and wider will enhance patient outcomes.

#### Conclusions

This original research has explored the experiences of occupational therapists and service users. The findings support the ongoing use of equipment for activities of daily whilst also recognising the need for future research.

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# List of Abbreviations

ACC	<ul> <li>augmentative and alternative communication</li> </ul>
ADL	- activities of daily living
AMED	<ul> <li>Allied and Complementary Medicine Database</li> </ul>
AOTA	American Occupational Therapy Association
APA PsycINFO	<ul> <li>American Psychological Association: PsycInfo</li> </ul>
Ax	- assessment
BJOT	- British Journal of Occupational Therapy
CEBM	Centre for Evidence Based Practice
CINAHL	<ul> <li>Cumulative Index to Nursing and Allied Health Literature</li> </ul>
СОТ	<ul> <li>College of Occupational Therapists</li> </ul>
COT <sup>2</sup>	<ul> <li>community occupational therapist</li> </ul>
DFG	<ul> <li>disabled facilities grant</li> </ul>
DH	<ul> <li>Department of Health</li> </ul>
FACS	<ul> <li>Fair Access to Care Services</li> </ul>
FAST	<ul> <li>Foundation for Assistive Technology</li> </ul>
FEW	<ul> <li>Functioning Everyday in a Wheelchair</li> </ul>
FIAT	<ul> <li>Family Impact of Assistive Technology</li> </ul>
GAS	<ul> <li>– Goal Attainment Scale</li> </ul>
GRADE	<ul> <li>Grading of Recommendations Assessment, Development and</li> </ul>
	Evaluation
HCPC	<ul> <li>Health and Care Professions Council</li> </ul>
HOT	<ul> <li>hospital occupational therapist</li> </ul>
IADL	<ul> <li>instrumental activities of daily living</li> </ul>
ICES	<ul> <li>integrated community equipment services</li> </ul>
IPA	<ul> <li>interpretative phenomenological analysis</li> </ul>
LHSH	<ul> <li>– long handled shoe horn</li> </ul>
MEDLINE	<ul> <li>Medical Literature Analysis and Retrieval System Online</li> </ul>
NHS	– National Health Service
OSA	<ul> <li>Occupational Self-Assessment</li> </ul>
OT	- occupational therapist
OTPD intervention	<ul> <li>occupational therapy Parkinson's disease intervention</li> </ul>
OTTOS	<ul> <li>Occupational Therapy Task Observation Scale</li> </ul>
QOL	- quality of life
QUEST	– Quebec User Evaluation of Satisfaction with Assistive
QULUI	Technology
חס	– Parkinson's disease
PD	- rainiisuiis uisease

PhD	<ul> <li>Doctor of Philosophy</li> </ul>
PIADS	- Psychosocial Impact of Assistive Devices Scale
REC	<ul> <li>research ethics committee</li> </ul>
RCT	<ul> <li>randomised control trial</li> </ul>
RCOT	<ul> <li>Royal College of Occupational Therapists</li> </ul>
RTS	<ul> <li>raised toilet seat</li> </ul>
THR	<ul> <li>total hip replacement</li> </ul>
TKR	<ul> <li>total knee replacement</li> </ul>
SCIE	- social care institute for excellence
SSOT	<ul> <li>social services occupational therapist</li> </ul>
ТОМ	<ul> <li>Therapy Outcome Measure</li> </ul>
UK	– United Kingdom
UKRIO	<ul> <li>– UK research Integrity Office</li> </ul>
USAT	<ul> <li>Usability Scale for Assistive Technology</li> </ul>
WFOT	<ul> <li>World Federation of Occupational Therapists</li> </ul>
WHO	<ul> <li>World Health Organisation</li> </ul>
WhOM	- Wheelchair Outcome Measure

#### **Chapter 1: Introduction**

The following chapter lays the foundations of this research project. It begins by revealing how an original concept developed into a research question supported by a clear set of objectives. It outlines the core philosophy of occupational therapy before exploring its relationship with activities of daily living and equipment. Definitions provide clarity and context alongside a developing rationale for the research. The chapter concludes with an outline of the thesis.

#### 1.1 Setting the Scene: A Personal and Professional Perspective

This research project was inspired by a professional background in the provision of equipment for activities of daily living (ADL), and personal family experience of providing care to an individual who utilised equipment. Prior to and following qualification as an occupational therapist I have worked with children, adults, and caregivers in a range of contexts. To varying degrees, all these roles involved the assessment for, prescription, and provision of daily living equipment for use in the home or community. As such, I have observed first hand, professionally and personally, the potential impact and role the provision of equipment may or may not have afforded others.

Reflecting back, I now recognise the impact equipment may have made to the lives of the care home residents I worked with in my late teens during the latter part of the 1980s and early 1990s. Particular examples refer to moving and handling equipment such as wheeled commodes, mobile hoists and slide sheets. At the time, such equipment was not readily available and only became more common when the importance of safe and effective moving and handling techniques was better understood in line with European Directives and associated regulations (Richmond 2005). In 1994, I was redeployed to the local authority community occupational therapy service following the implementation of the Community Care Act 1990 (Great Britain. Parliament 1990) in 1993 which resulted in the residential unit closing.

In recent times I have observed the advent and continued period of efficiency savings alongside changes to national and local policy, and drivers such as the introduction of Fair Access to Care and invest to save initiatives. These, coupled with clinical experiences induced further consideration of the equipment I had assessed and provided. Though there are numerous examples, one I strongly recollect refers to the time I spent working with a gentleman diagnosed with a deteriorating condition. I recall much of the early conversations focussed on the equipment and environmental 'needs' of the service user. As such discussions centred on mobility and bathing equipment, beds, ground floor facilities, wheelchairs, and ramps. As I spent more time with the service user and his wife I observed what appeared to be, from my perception, their obsession with installing a ground floor toilet and bathroom. The family were fixated with obtaining quotes and commencing the extensive works. What became more and more apparent to me was the lack of time the gentleman had and the realisation that the work would not be finished, if even started, in time for him to use it. At the same time, the referring consultant was demanding to know when the hospital style bed would be delivered despite my advising that the service user had at that time declined the equipment. The combination of the two factors began to evoke a strong sense of almost wrongdoing and a professional disservice to the service user, his wife and close family who were also being pulled into the situation. As an occupational therapist I had been drawn into trying to fix the issue with physical objects and had begun to lose sight of my core professional values and beliefs. This was a tremendous shock to me. While environmental conversations continued, there was a shift to the smaller things such as focussing on how he could spend more time with his family and doing the things he enjoyed. The gentleman indeed passed away before the works commenced.

As such I began to question whether 'equipment' now represented the needs of the organisation and thereby through association, my clinical practice and the occupational therapy profession, rather than that of the population they are intended to serve. In essence, I was increasingly querying whether 'equipment' now centred on organisational and professional processes and procedures rather than the requirements of patients and caregivers. As a clinician there is little opportunity to discuss outcomes with service users and their caregivers. Much of the feedback is anecdotal or in the form of passing comment. Knowing whether and to what extent occupational therapy input and equipment impacted on the ability of service users to complete their desired occupations and the meaning they attached to this was largely, if not wholly, unknown. As my thoughts developed further, I began to ruminate how as a clinician, I 'knew' whether the equipment provided affected or impacted on the lives of my patients. Based on my perceptions, I believed the provision of equipment did positively influence the well-being of my service users. However, I contemplated whether from the patients, family, and caregiver's perspectives this was the reality. Informal discussions with colleagues indicated a perceived shift between the landscape of daily living equipment, the relationship between it, and the nature and ethos of occupational therapy. For example, the consensus amongst colleagues indicated a shift in the volume of and complexity of equipment provided over time. Whilst the

availability and improved technical functionality of equipment was welcomed the motives and impetus behind the volume provided by some quarters was questioned. In time, my thoughts and reflections morphed into a professional curiosity and desire to explore the subject in more detail, hence the inspiration for this research.

During the process of completing my doctoral studies my professional journey has seen some changes. Upon its commencement I worked for the National Health Service as a senior clinical/practitioner before moving into a senior lecturer role for a short period of time. Due to personal circumstances, I returned to a clinical practitioner role as an employee of a social enterprise which provides a range of community health and social care services. Throughout my research journey I have chosen to remain purposefully grounded in clinical practice and with those it serves, namely the service user. Whilst my role in academic practice was professionally fulfilling and provided invaluable direct access to research resources such as my colleagues, I believed it important to remember where my interest in the subject began. I am and always will be an occupational therapist. As such, the research 'lens' centres around the perspective of an occupational therapy practitioner. Additionally, the majority of my pre-qualification and professional career has involved equipment and adaptations. Whilst my current post is within rehabilitation and enablement services I remain drawn to the equipment component of my clinical practice and remain passionate about my perception of its value. I am equally passionate about its use in moderation as a tool to enhance occupational independence and outcomes rather than one which creates dependence.

## **1.2 Exploring and Defining the Context**

As the scope of occupational therapy practice broadens, so does the language and terminology involved. Equally, as our knowledge and understanding of areas of clinical practice advances, language and terminology is created and adapts correspondingly. The following sections (1.2.1 through to and including 1.2.7) therefore guide the reader through the terms most associated with occupational therapy and ADL equipment relevant to this research project.

#### 1.2.1 Occupation and Occupational Therapy

Historically, there has been a notable debate within the profession of occupational therapy around what defined the concept of 'occupation'. Some argue the term is too broad and thereby results in a lack of understanding within the profession, whereas others suggest this lack of clarity highlights the complexity of and compliments the variance of human nature (Molineux 2010). According to Polatajko (2014), past occupational therapy practice focussed on impairment rather than attempting to

understand our lives from an occupational perspective. This interpretation of occupation as a 'medical treatment' approach is at odds with the origins of occupational therapy as a means of 'occupying people'. Both of these historic uses of occupations challenge our current efforts to shift our understanding of the term. Equally, for those outside the profession of occupational therapy the term 'occupation' is often construed to involve some form of paid activity or employment. Curtin et al (2017) suggested caution when comparing the current and past use of occupation as a therapeutic intervention due to recent advancements in our understanding of the concept. Molineux (2010) argued that being occupationally engaged involves both physical and cognitive effort with any chosen task or activity, whether paid or not. It is widely acknowledged that for an activity or task to be considered a true occupation, it must be purposeful to the individual completing it (Molineux 2010, Curtin 2017). Equally, individuals are more likely to actively engage in occupations which have a purpose and meaning (Molineux 2010). Additionally, there is a growing recognition of the 'darker side of occupation' which acknowledges chosen activities may not fit the traditionally accepted link between occupation and health (Twinley 2013, Hitch 2014a). Whilst the wider literature offers several definitions of 'occupation', there is no universally accepted version (Molineux 2010, Turpin 2017).

The Royal College of Occupational Therapists (RCOT) described rather than defined 'occupation' as a range of tasks and activities, encompassing leisure, self-care, or work, which are purposeful, practical, and which enables independence (RCOT 2019a). This broad description included all potential elements of life's occupations. It allows individuals to select occupations which they identify as important to them. Most definitions offered in the literature, including that referred to by Polatajko et al (2013), tend to encompass similar language to that provided by the RCOT. Similar in context the simple definition of 'doing, being and becoming' was proposed by Wilcock (1998) who later developed this to include the term 'belonging' (Wilcock 2006). Recent literature such as Hitch et al (2014b), outlined occupational therapy's current understanding of the four concepts of occupation as:

- 'Doing' which involves the act of engaging with occupation/s and includes those which are meaningful, how we can adapt to, and achieve them.
- 'Being' relates to our sense of self which is influenced by our occupations which may or may not be completed through choice.
- 'Becoming' addresses how we as humans develop over time dependent on our occupations and what we hope to achieve from them.
- 'Belonging' involves our perceived or known relationships with others and occupational context.

A critical analysis conducted by Hitch et al (2014a) explored the relationship between the four concepts of occupation. It identified an interdependence between the four concepts of doing, being, becoming, and belonging which supports the holistic approach of occupational therapy practice.

In 2004, the United Kingdom's (UK) College of Occupational Therapy (COT), the national body of occupational therapists as it was then known, defined occupational therapy as facilitating "people to achieve health, well-being and life satisfaction through participation in occupation" (World Federation of Occupational Therapists, WFOT 2018, p66). In 2019 the RCOT described occupational therapy as "a whole person approach to both mental and physical health and wellbeing and enables individuals to achieve their full potential" (2019a, p1). Others described occupational therapy as enabling people, as individuals, to engage or participate in activities which are meaningful to them as part of their daily life routines (Polatajko et al 2013, WFOT 2010). The RCOT referred to the use of meaningful and purposeful activities to facilitate individual and community participation in occupations with the overarching aim of improving quality of life by promoting functional independence, general health, and well-being (RCOT 2019a; RCOT 2019b; RCOT 2020a).

In the UK, the occupational therapy profession has been referred to in key documents, including National Service Frameworks (Department of Health, DH, 2001; DH 2005) and social care policy (DH 2008) as a means of reducing the need for additional community-based services, such as home care, by maintaining or improving independence (Boniface 2013). Guidance published by the COT (2016a; 2016b) outlined the direct relationship between occupational therapy practice, equipment, and The Care Act 2014 (Great Britain. Parliament 2014). Using case studies and service user testimony a report published by the COT (2016c) highlighted how occupational therapy input has the capability to improve service user outcomes whilst positively affecting hospital pressures by reducing admissions and facilitating swifter discharge. The Royal College has urged service providers and commissioning bodies to both recognise and utilise the skills of occupational therapists more effectively to develop and enhance the service user journey and outcomes.

#### 1.2.2 Occupational Therapy Roles

Within occupational therapy services there is a broad range of levels and clinical experience. The general distinction is between those with a professional qualification in occupational therapy and those without. Newly qualified therapists (typically a band 5 in the UK) commence their professional careers by beginning to consolidate their

knowledge and understanding of the theory and experiential learning they studied at university and whilst on practice placements. Career progression is then dependent on the career objectives of the individual and the opportunities available in combination with competencies, skills, and experience.

Senior occupational therapists (band 6 and or 7) normally have responsibility for clinical leadership or a management role, dependent on the structure of their employing organisation. Occupational therapists above a band 7 are generally in a clear management or consultant role. Staff without a professional qualification, again dependent on the organisation, are recruited to a range of roles. These include technical instructors (band 4), assistants (band 2 or 3) and support workers (band 2). As the scope of occupational therapy practice continues to increase the range of available roles is likely to broaden over time. How these are referred to will be dependent on the employing organisation.

Level of responsibility is dependent on experience and service expectations of the given role. Though it is likely that qualified and unqualified staff members will progress through bandings this is not an expectation. As such, gualified occupational therapists may choose to remain in a band 5 or 6 position and gain levels of experience which may not necessarily be reflected in their banding. Though unqualified staff members are often highly skilled they do not receive the same level of training as gualified therapists. For example, occupational therapists are dual trained (physical and mental health), they explore and understand the person, their occupations, and the environment. The ability to analyse activity is a key component of occupational therapy assessment and treatment planning as is clinically reasoning our decisions. In brief, activity analysis is a core occupational therapy skill (Hagadorn 2000; 2001, Duncan 2021) which requires the therapist to break down and analyse the component parts of an activity or occupation. The outcome of these enables the therapist to identify issues and areas of concern and problem solve solutions accordingly (Duncan 2021). Occupational therapy texts define clinical reasoning as "the reflexive thinking associated with engaging in a client-centred professional practice" (Unsworth 2021, p180) or, "the process that practitioners use to plan, direct, perform, and reflect on client care" (Schell 2009, p314). As with many core professional skills the art of adapting our approaches and outcomes is dependent on the situation and context which includes activity analysis and clinical reasoning. Whilst staff without a professional qualification may have a broad understanding of these, the depth of understanding and their ability to apply this can be limited. Although this research project recognised the capability of all occupational therapy staff members it is primarily

interested in the skills of the occupational therapist to assess for, prescribe, and provide equipment for activities of daily living. The focus of the literature review (Chapter 2) and the main research project was therefore centred on those with a professional qualification in occupational therapy.

The potential role of an occupational therapist is increasingly varied. Traditionally, occupational therapists worked within mental or physical health and social care services. However, roles now include a range of role emerging contexts. Examples include prisons, emergency services and response teams, refugees and asylum seekers (Shiino and Hasegawa 2011, Trimboli 2011, RCOT 2019a). Occupational therapists work with all age groups in primary, secondary and community environments such as schools, day services, and the wider community. They complete diverse assessments to identify areas of occupation which individuals are no longer able to complete to the same level or skill as they were previously. Patient-centred interventions are designed and selected to assist the individual to return to their optimal level of everyday functioning. This can involve adapting or learning new skills whether for the purpose of physical, cognitive, or mental health, amongst others. Interventions focus on play, budgeting, leisure, work, routines, self-care, problem solving, parenting, and adapting environments (RCOT 2019a). Ultimately, the goal is to enable individuals to reach their full potential.

The American Occupational Therapy Association (AOTA) (2020) divided occupations into nine broad areas, two of which involved activities of daily living – activities of daily living (ADL) and instrumental activities of daily living (IADL). These are discussed in detail in Section (1.2.3) below. The remaining categories included, health, rest and sleep, education, work, play, leisure, and social participation (AOTA 2020).

#### 1.2.3 Activities of Daily Living

As with many terms used by health and social care, 'activities of daily living' (ADL) are often defined dependent on clinical areas of practice (WFOT 2012). As such, occupational therapists and others understanding and perception of ADLs may include activities which can be completed in a range of physical environments including the community, at home, and leisure. For example, the consensus of 36 (95%) occupational therapy staff who participated in a survey local to this research indicated that ADLs involved any activity (including personal, domestic, leisure, play and work) completed by an individual as part of their chosen everyday activities. The following excerpts represent a small sample of the definitions offered by participants in the survey: "activities essential or desirable for a meaningful life", "any activity carried out

as part of a daily routine which the client feels is important to them" and "functional tasks of daily life". According to Lock (2002), the earliest recorded use of the phrase 'activities of daily living' within the UK had been sourced to a government disability publication in 1955.

Potentially the list of ADLs is infinite as it could be argued that any activity chosen and completed by an individual is an activity of their daily life (James 2009). However, the AOTA (2020) defined ADLs as the regular attendance individuals pay toward maintaining personal hygiene, nutritional intake, evacuation of the bladder and bowel, dressing and sexual activity. They described other activities which related directly to an individual's home and community as an IADL, examples included, childcare, shopping, religious and spiritual needs, and caring for others and pets (AOTA 2020).

Individuals experiencing difficulties in these or other areas may receive advice, a period of enablement/reablement, rehabilitation and or equipment designed to ease or improve functional performance. For clarity, enablement and reablement interventions are typically provided by non-qualified staff who are trained to support people to reach their potential. The key purpose of enablement and reablement is to enhance independence by 'doing with' rather than 'doing for' which is the premise of standard care support services. In contrast, rehabilitation services involve specialist therapy assessment and treatment programs led by qualified therapists including occupational and physiotherapists. If requested, therapists will support the enablement and reablement and reablement and reablement end care Excellence 2017; Social Care Institute for Excellence, SCIE, 2020).

Though reputedly instigated by the medical profession during the late 1940's and early 1950's the association between activities of daily living and occupational therapists was primarily developed by the occupational therapist Grizel McCaul at Kings College Hospital (Jay et al 1992, Lock 2002, Hocking 2008a). The impetus for change appeared to be led by the suggestion that previously little consideration for improved or alternative treatment techniques was given to those with a traditionally nonpaid work role, for example housewives (Lock 2002, Hocking 2008a). Richardson (1952), a senior registrar at St Thomas's Hospital, corroborated this when suggesting doctors historically failed to acknowledge the possibility that forms of treatment supplemental to their own was beneficial. Richardson (1952), and colleagues, began to accept how activities, including personal care, were an important element of recovery. He recommended the occupational therapy profession was best placed to support this

change of opinion due to their rehabilitative skills and ability to design various implements and devices to facilitate independence. A report by Cooksey (1954) highlighted how housewives were able to return to their domestic activities of daily living following adjustments made to household appliances and learning to compensate for any changes in their physical capabilities. Such was the success of using activities of daily living as a treatment modality that by the end of the 1950s it was regarded as established occupational therapy practice (Hocking 2008a).

#### 1.2.4 Quality of Life

Over time, the emphasis on measuring quality of life (QOL) outcomes within health and social care has increased exponentially. The increased interest is linked to developments in advanced healthcare treatment and management (Post 2014). However, due to its subjective nature, as with many terms used in health and social care, there is considerable debate within the literature surrounding a clear definition of QOL. This lack of consensus is widely discussed, examples include Post (2014) and Baron (2019). In the absence of definitive agreement, the definition offered by the World Health Organization (WHO 2021) is commonly referred to:

"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".

As the concept of QOL has developed from a biomedical perspective to one with a broader biopsychosocial approach the number of domains it addresses has increased. According to the findings of a literature review conducted by Baron et al (2019) these include: physical, social, and psychological domains. Equally, as our understanding has developed there is a greater acceptance of the difference between QOL and health related QOL factors, with health related QOL measures providing objectivity, and other QOL measures focussing on the subjective perspective of the individual. However, despite this, inconsistency remains (Baron et al 2019).

With the notion of subjectivity in mind, personal observation in the clinical field indicated QOL could be affected by the provision or non-provision of equipment. As such, the concept of QOL was a tacit factor associated with the rationale for this research project.

#### 1.2.5 Compensatory Approach

Where the restoration of previous levels of function are compromised, a compensatory or adaptive approach involves modifying how an individual conducts and completes an

activity. This involves the modification of an activity to accommodate changes to physical and or cognitive functioning which may include adapting technique, the environment, and the provision of equipment (Hersch et al 2005, Feaver and Ezekiel 2012, RCOT 2018a).

#### 1.2.6 Equipment and its Relationship to Occupational Therapy: an insight

The restorative value of therapeutic activities and occupations dates back two millennia (Licht 1948), and further (Turner 1996, Wilcock 2001, Wilcock 2002, Paterson 2014), with a recognised close association or alignment to the medical profession (Casson and Foulds 1955). The profession of 'Occupational Therapy', now recognised globally (WFOT 2019), began to emerge during the early 19th century (Craik 1992, Mayers 2000, Wilcock 2001, Paterson 2007) originating in sanatoria and other institutions for individuals with mental ill health (Groundes-Peace 1957, Wilcock 2002).

The long-term use of 'equipment' as an intervention to improve health and engagement in activities is evident within the literature. For example, in 1908, Smith discussed the use of 'medical equipment' when describing his experience of examining 5000 year-old Egyptian 'splints' for upper and lower limb fractures. Pellegrino, is credited with developing a typewriter for a visually impaired friend in 1808 (Magar 2011, Reinhart 2014, Cook and Polgar 2015) while Braille invented a machine of the same name in 1821 (Magar 2011) and Bell created the audiometer in the 1880s (Cook and Polgar 2015, Hochfelder 2020).

What could be described as 18<sup>th</sup> century 'occupational equipment', is alluded to in several published papers including those of Licht (1948) and Hill (1967). The occupations cited are singing, reading, exercise, music, gardening, laundry, and workshop (woodwork) tasks (Licht 1948). By association, the 'equipment' required would have included: books, musical instruments, spades and hoes, lathes, and hammers. Spinning wheels and implements for sewing and knitting are other early examples (Groundes-Peace 1957).

In the UK, the use of craft and workshop-based activities during the early 1900s into the 1940s, for those experiencing physical deficits or issues related to their mental health, is well documented (Casson 1938, Jackson 1938, Rivett 1938, Ross 1939, Hick 1940, McCaul 1944, Hick 1948, Casson 1955a, Casson 1955b, Lockhart 1957, Lock 2002, Turner 2002, Hocking 2007; 2008a); this included work with soldiers injured during the First World War (Wilcock 2002). A series of archival reviews (Hocking 2007; 2008b) remarked on the development of occupational therapy during the Second World War particularly in relation to how the public and Government of the time perceived disability. Hocking (2007; 2008b) suggested a more proactive Government encouraged a greater vocational philosophy toward treatment, based upon industrial tasks rather than craft-based activities. As such, this shift in treatment attitudes was designed to ensure decommissioned service personnel were, where possible, able to return to some form of paid industrial employment (Hocking 2007; 2008b) and thereby assist with boosting the depleted economy (Lock 2002). The argument for the use of realistic occupational treatments was made by Cooper (1940) who suggested embroidery closely represented a more affordable work activity, post-discharge, compared to those of weaving and bookbinding which required specialist less affordable materials and tools.

A key political change in the 1940s, namely the inception of the National Health Service (NHS) in 1948, (Paterson 1998, Paterson 2012) was a probable driver of the development of occupational therapy and its services. Patients, particularly in a physical rehabilitation context, were increasingly likely to be exposed to and treated by occupational therapists developing and providing daily living interventions. The likely consequence of this would have been an increased exposure to the gadgetry and equipment of the time. The founding of the NHS had an impact on statutory wheelchair provision previously limited to soldiers injured during the First World War, and non-military citizens injured during the Second World War (Silcox 1995).

In the 1940s, the occupational therapist Grizel McCaul was drawn toward using enabling equipment for individuals with a disability and equally concerned with how these items may assist service users to regain their independence (Lock 2002). At the same time, the national movement away from heavy machinery as a rehabilitative treatment option coincided with the expansion or transformation of facilities for the purpose of daily living activities alongside a shift toward community visits (Jay et al 1992). During this time, occupational therapists were demonstrating and combining their practical and problem-solving skills with those of innovation to develop alternative functional techniques, designing gadgetry and small devices, and by modifying or rearranging the home environment (Hocking 2008a).

Several gadgets were developed during the 1950s and 60s. Instructions on how to produce them can be found in the occupational therapy journals published during this time. Examples included: a tin opener (Anon 1957) and a combined kitchen trolley and walking frame (Boak 1958). Extensive lists of equipment and their purposes are available. Birkbeck's (1953) paper included items designed for domestic activities and

personal care, work-based activities, and leisure, whereas Brown (1959), concentrated on equipment designed to assist with independent dressing. Richardson (1952) reported on the display of over 100 gadgets during an exhibition and Letcher (1962) provided detail of a door opener designed by a patient. An increase in home visiting by occupational therapists supported the accuracy of environmental modifications created or fabricated by family or occupational therapy departments (Hocking 2008a, Lock 2002). This was common practice at the time as few items of equipment were available for purchase (Lock 2002). During the 1950s the Ministry of Health was responsible for the provision of equipment and "petrol driven chairs" (Lock 2002, p267) whilst the Local Welfare Authority was responsible for the completion of home adaptations for daily living.

Further examples of occupational therapy equipment or gadgets within the literature included door openers, handwriting rests, elastic shoelaces, vegetable boards, modified knifes and cutlery holders, wooden furniture raisers, stocking aids and adapted nail brushes (Lock 2002, Hocking 2008a). According to Hocking (2008a) opportunities to improve independence through the combined use of equipment and activities of daily living was not unnoticed within the profession and government committees. The change in practice from craft-based activity to that of equipment and machinery was not however supported by all therapists of the time (Turner 2011). As such, despite the growing interest and use of daily living interventions the use of craftbased activities, workshop equipment, and industrial machinery continued to be evidenced throughout the 1950s (Lock 2002). The biomechanical principles of this equipment type continued to suit the medical model approach to treatment, and consequently, could still be found in many occupational therapy departments throughout the mid-to-late 1990s (Turner 2002). During this time period, Turner (2011) highlighted their perception of a short-sighted decline of craft-based activities and production of craft items which failed to correspond with changes in advancing treatment approaches.

Bartholomew (1955) advocated the use of adaptive equipment for ADLs where normal movement or positioning could not be achieved along with activities such as weaving, carpentry and basketry. Other items utilised by paediatric occupational therapists of the time included: 'magnetised or weighted toys' (p15), mobility equipment and clothing, tables lined with felt, typing sticks, letter and peg boards (Bartholomew 1955). Discussion surrounding the use, or non-use of adaptive equipment or modified furniture, particularly for those with cerebral palsy, was raised by Bartholomew (1955) and later Hocking (2008a).

The progress made by McCaul and Cooksey at the King's College Hospital during the 1960s, in relation to ADLs, was acknowledged by the physician Zinovieff (1962). Zinovieff (1962) offered his observations of the equipment provided at the time – with some being made use of and some which were not – a point some may argue remains relevant today. Others continued to describe the use of workshops as a treatment mode (Lock 1961). One paper outlined the use of a 'shapeboard' for the treatment of hemiplegia, hand injuries and cognitive assessment (Thornely 1962). The shapeboard was made by a service user receiving treatment for a hand injury; they would have required access to a workshop and tools.

During the late 1970s, there was a shift between papers published in the British Journal of Occupational Therapists (BJOT) which described equipment and their uses to those which reported on clinically based research outcomes. In fact, a paper by Ravetz (1987) highlighted the limited volume of published research, including that of equipment, available prior to the 1970s. Ravetz (1987) implied that equipment-based research may have increased during the-mid-to late 1970s in direct response to the BJOT encouraging therapists to complete research in response to the implementation of the Chronically Sick and Disabled Persons Act 1970 (Great Britain. Parliament 1970). Paterson (2012) described the development of social work and social services departments, which included occupational therapy, during this time frame. Paterson (2012) associated this with an increase in the volume of equipment-based research which is explored in more detail in Chapter 2. Literature exploring the use of Fair Access to Care Services (Lett et al 2006) and a critical literature review (Boniface et al 2013) suggested that historically occupational therapists were compelled to be involved with equipment provision and adaptations due to statutory parliamentary legislation such as the Chronically Sick and Disabled Person Act 1970 (Great Britain, Parliament 1970). In comparison, Lett et al (2006) and Boniface et al (2013) suggested the affiliation between occupational therapy and equipment was an adverse and direct consequence of policy on practice. Wielandt and Strong (2000), Chamberlain et al (2001) and Brittle et al (2007) favourably described the assessment and provision of equipment as core to occupational therapy interventions. Recent literature has suggested a subtle change in the perception of occupational therapists who now view equipment as a means of facilitating occupation rather than a method of addressing disability (Pain and Pengally 2010). There has and continues to be a clear shift of paradigm which observes current occupational therapy practice transforming from a medical model toward a social model and now to one which is occupation-focussed (Swain and French 2010, Laliberte Rudman and Aldrich 2017). Further evidence to

support this can be found within professional literature describing the role of occupational therapists (WFOT 2019, WFOT 2020).

#### 1.2.7 Equipment Defined

Historically, the terms 'aid/s' and 'equipment' were used singularly or in combination to describe a range of items provided to, or used by, those with a physical disability or mental health condition. Though remaining in use today, anecdotally the literature suggests that during the 1980s the term 'aid/s' appears to have been used less widely with 'equipment' becoming the more prominent of the two. More recently, due to rapid technological advancements, the term 'equipment' is being replaced by the phrases 'assistive device' (Pain and Pengelly 2010), 'assistive products' (World Health Organization, WHO, 2018), 'adaptive equipment' and 'assistive technology' (Evans et al 2011) with assistive technology considered by some as the umbrella term (Pain and Pengelly 2010, Evans et al 2011, WHO 2018). This change in terminology is noticeable within national and international literature. However confusion arises within the literature as these and other terms, such as telecare and telemedicine, are frequently used interchangeably to describe the same items (Doughty et al 2007; Foundation for Assistive Technology, FAST, 2014).

Pain and Pengelly (2010) described an assistive device as a product which, through its design, is intended to promote independence in areas such as "self-care, leisure and productive occupations" (p453). In contrast, FAST (2014) used the definition "Assistive technology is any product or service designed to enable independence for disabled and older people" (p1). An alternative definition for assistive technology offered by the WHO is: "any device or system that allows an individual to perform a task that they would be unable to do or increases the ease and safety with which the task can be performed" (2004 p10). An older more simplistic definition was provided by George et al (1988) when citing Goble and Nichols (1971) who summarised equipment or 'aids', as they were then known, as "any item designed to help functional ability" (p1365). George et al (1988) proceeded to describe adaptations as "aids that are fixtures in the home" (p1365). With such a range of terms and definitions it is reasonable to expect confusion to arise regarding what constitutes equipment or assistive technology, and telecare or telemedicine. Equipment, assistive devices, or technology have a tendency to encompass items such as: environmental control systems, bathing and toileting equipment, spectacles, and ramps. In contrast, items such as patient alarms (for example safety pendants and other forms of sensors/detectors) fall under the term of telecare, and devices designed to monitor physiological parameters (such as blood pressure, diabetes and asthma) from remote or separate locations are known as

telehealth (Doughty et al 2007, WFOT 2014). Telemedicine provides the opportunity to conduct electronically based consultations via a device such as a computer. Telecare and telemedicine based technology does not traditionally fall within the scope or remit of occupational therapy practice.

The UK Government differentiated assistive technology into that which is designed as either a medical device or as an 'aid for daily living' (UK Government, Gov.UK, 2019, p3). Identifying into which group the device falls is dependent upon its intended primary purpose which is recorded by equipment manufacturers. Examples of medical devices include mobility equipment such as wheelchairs, crutches, walking frames and sticks, slide boards, items for pressure and posture management, stand aids, and patient hoists including those which are integrated with baths.

Overall, the purpose of any device is to improve an individual's occupational performance and quality of life irrelevant of context and the environment (WHO 2018). For many, where an occupational need or deficit exists, equipment often becomes the key component in facilitating the ability of individuals to perform their desired occupations (Goodacre and Turner 2005) and to remain in their own home whether independently or with support. In essence, equipment is provided to bridge occupational performance deficits so enabling individuals to engage or participate in activities or tasks. Occupational performance refers to the ability of an individual to appropriately select, perform and complete tasks and activities relevant to their lifestyle (Townsend et al 2002, Crabtree 2003).

Equipment provision is likely to vary dependent upon clinical speciality and the context in which occupational therapists work. For example, hand therapists are more likely to concentrate on items such as splints and offer advice on adapted cutlery and writing implements. Community based occupational therapists tend to provide equipment for daily living activities such as rails, bath seats and kitchen equipment, whereas others may specialise in wheelchairs and specialist seating. Equipment for daily living activities traditionally provided or recommended by occupational therapists can be divided into two types, those which are portable such as raised toilet seats, perching stools and slide boards and those which are fixed such as rails and stairlifts. Others which can be portable or fixed include toilet surrounds, ramps, and patient hoists.

In 2018, the WHO reported over one billion people worldwide required access to at least one assistive product. They anticipated this would increase in less than 15 years,

to over two billion people requiring at least one device, with those they describe as 'older people' benefiting from a minimum of two.

To avoid confusion, whilst recognising the distinction made between medical devices and assistive technology, the items discussed within this thesis will predominantly relate to daily living activities and will be referred to as 'equipment'.

#### 1.3 Measuring the Benefits

Measuring outcomes is a core expectation of clinical practice, including occupational therapy. Outcome measures provide information demonstrating change over time which can be associated with a specific or series of interventions. The data collected can be used to demonstrate improvement, maintenance, or deterioration in an individual's ability to engage with or participate in their chosen activities (Bullock 2014, COT 2015a, Enderby and John 2015). The data collected has the potential to inform managers, the research and evidence base, commissioning bodies, and clinical audit of the benefits, or not, of clinical interventions. Outcome measures can be completed by the clinician or the service user (Bullock 2014, COT 2015a), with the latter option becoming increasingly preferable (Laver-Fawcett 2014, COT 2015a). Outcomes can be non-standardised or standardised, however of the two, standardised outcome measures are considered the most desirable and credible (Laver-Fawcett 2014, COT 2015a). The COT (2015a) recognised the weight afforded to standardised measures over those which are non-standardised particularly by some professions, whereas others report the use of non-standardised outcome measures are now considered unacceptable to those who fund or commission services (Laver-Fawcett 2014). In the researcher's experience, outcome measures tend to capture information which is translated into numerical data. It could be argued this dilutes impact and does not adequately capture the experience and meaning of provision or interventions.

There are a wide range of outcome measures available for use by occupational therapists, several of which were recognised by the COT in their Research Briefing, Measuring Outcomes (2015a). None of those listed are equipment or assistive technology specific. Other outcomes not listed include: the Goal Attainment Scale (GAS) (Kiresuk and Sherman 1968), the Occupational Self-Assessment Version 2.2 (OSA) (Baron et al 2006), the Therapy Outcome Measure (TOM) (Enderby and John 2015) and the Occupational Therapy Task Observation Scale (OTTOS) (Russell et al 1996, Bullock 2014).

Outcome measures designed specifically for equipment include: the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers et al 1999), the Psychosocial Impact of Assistive Devices Scale (PIADS) (Day and Jutai 1996), the Usability Scale for Assistive Technology – Wheeled Mobility (USAT-WM) (Arthranat et al (2009) and the Family Impact of Assistive Technology (FIAT) (Ryan et al 2006). The Wheelchair Outcomes Assessment Tool for Children (WATCh) is a recently developed tool for specific use with paediatric wheelchair users (Tuersley et al 2018). A second assessment tool, the WATCh-Ad, has since been developed for adult wheelchair users.

Due to an identified lack of suitable outcome tools, the QUEST was developed through the mid-1990s to capture individual perception of the satisfaction or dissatisfaction of the use of assistive devices (Demers et al 1999). Research has since been conducted to explore its content and construct validity and reliability for use in a range of diverse countries (Demers et al 1999). However, the QUEST focuses on the technical design and use of the equipment over issues such as impact and benefits. The QUEST 2.0, developed by Demers et al (2000) is now widely used.

Kenny and Gowran's (2014) critical appraisal identified a total of five outcome measures for use in seating and wheelchair provision. Of the 49 papers they identified, eight were related to assistive technology and 12 to wheelchairs. Of these, five measures were included and subsequently reviewed, these were the Wheelchair Outcome Measure (WhOM) (Mortenson et al 2007), Functioning Everyday in a Wheelchair (FEW) (Mills et al 2002), the GAS (Ottenbacher and Cussick 1993), PIADS (Jutia and Day 2002) and the QUEST (Demers et al 1999). The first two of these outcomes were described as wheelchair specific with the remaining three as generic. The four areas explored were: client-centredness, psychometric properties, responsiveness and sensitivity, and administrative burden. No singular measure was found to be sensitive enough to meet the specific needs of the therapists. As such, Kenny and Gowran (2014) recommended services must identify well-defined outcomes linked to context-specific sustainability. The lack of sensitivity of equipment and adaptation outcome measures was previously highlighted by Heaton and Bamford (2001). The seven measures they referred to were not included in Kenny and Gowran's (2014) later paper which may indicate some attention to developing measures more appropriate to context but which according to Kenny and Gowran (2014) continued to lack specificity. Both Heaton and Bamford (2001), and Kenny and Gowran (2014) suggested that given the absence of a singular measure and the range and diversity available, the use of multiple measures are most effective in capturing the required data. When referring to occupational therapy practice outcomes Laver-Fawcett (2014)

argued that occupational therapists should select outcomes which address satisfaction, participation, performance, and service outcomes; they highlighted the lack of sensitivity found with the available outcomes, including those related to cultural differences.

#### 1.4 National and Local Context

Historically, equipment services were divided between health and social care provision. Whilst the Health Act 1999 (Great Britain. Parliament 1999) was designed to promote the development of integrated health and social care equipment services, known as Integrated Community Equipment Stores (ICES), the processes involved in bringing these stores into fruition resulted in a significant amount of time passing before becoming reality. In the local context, in which the present research was conducted, equipment is accessed via an ICES or the wheelchair service dependent on locality within the Trust. Whilst housed in the same physical environments and sharing backroom staff the two equipment budgets are currently separate with no known plans to share resources other than the physical environment. Large equipment items such as stairlifts, through-floor lifts and modular ramps are accessed via the Disabled Facilities Grant (DFG) scheme which involves a test of resources to determine eligibility for funding. At present however, within the locality of this research, the test of resources is currently being waived. The rationale for this is unclear as is how long this will continue.

A report published by the Audit Commission in 2000 recognised the quality of some community equipment services whilst also highlighting inequality in many others. Some of the key points raised included: poor recognition of the benefits of equipment, disparity of provision between geographic areas, poor levels of funding, and a lack of engagement with service users. The report offered a range of recommendations intended to improve the quality of integrated community equipment services.

The Fair Access to Care Services (FACS) framework was introduced in 2002, and fully implemented in 2003 to establish equity across all local authorities (SCIE 2013). The four levels or thresholds of eligibility were: critical, substantial, moderate, and low; these were non-negotiable. However, local authorities were able to determine their own threshold for provision. As such, one local authority may have chosen to provide services to individuals in all four categories, whereas in the neighbouring authority, service provision could have concentrated on those in the critical and substantial categories. Whilst all members of the population were entitled to an assessment of need, inequality remained regarding provision of equipment and other services such as

home care. For example, in one authority, service users were entitled to equipment provision irrelevant of the category whereas others who found themselves in the lowest threshold were not. Concerns were raised in relation to authorities using the opportunity to set their own thresholds to justify provision which many believed was based purely on the availability of financial resources. The FACS framework has now been replaced by the Care Act 2014 (Great Britain, Parliament 2014).

The Care Act 2014 (Great Britain, Parliament 2014) replaced, amongst others, four key pieces of legislation relating to the provision of equipment: the National Assistance Act 1948 (Great Britain, Parliament 1948), the Chronically Sick and Disabled Persons Act 1970 (Great Britain, Parliament 1970), the National Health Service and Community Care Act 1990 (Great Britain, Parliament 1990) and the Disability Discrimination Act 1995 (Great Britain, Parliament 1995). Its purpose to combine a range of existing, outdated laws relating to health and social care into one which is less complex to navigate and interpret (Department of Health and Social Care 2016). The National Assistance Act 1948 (Great Britain, Parliament 1948) assured local authorities of their power to provide assistance to those with a 'permanent and substantial disability', whereas the Chronically Sick and Disabled Persons Act 1970 (Great Britain, Parliament 1990) turned this power into a duty to provide (Haworth and Hopkins 1980). The NHS and Community Care Act 1990 (Great Britain, Parliament 1990) provided local authorities with a duty to complete an assessment of need. It encouraged individuals to remain in their own home for as long as practicable rather than transferring a need for care into a residential or nursing establishment. However, literature exploring the effectiveness of the application of these former Acts by local authorities found significant irregularities regarding their implementation (Keep and Clarkson 1994). A prior report completed by Griffiths et al (1983) earlier highlighted concerns with inefficient use of resources and funding inadequacy. Other than reference to equipment and technology in existing government and other organisational reports there are no current guidelines or policies specific to assistive technology. Though there is a Code of Practice related to equipment services, authored by Donnelly in 2015, it is unknown whether this is 'consulted' by organisations and commissioners of services.

Assistive technology, which includes mobility equipment through to a range of electronic devices such as environmental control systems, is acknowledged by the Equality Act 2010 (Great Britain, Parliament 2010) as reasonable adjustments which can be made to reduce the potential for discrimination against individuals with a disability. By law, the NHS has a duty of care to ensure people with disabilities have

free access to equipment such as augmentative and alternative communication (AAC) and wheelchairs as a statutory provision.

Local to this research project, in 2015, a combined integrated community equipment and demonstration centre opened. The space incorporates dedicated 'rooms' (a bathroom, kitchen, lounge and bedroom) which display a range of ADL equipment which can be demonstrated and trialled by visitors. Information and advice are offered by members of the community therapy team who hold regular clinics at the centre. The building houses the integrated community equipment store funded jointly by local health and social care. Equipment, provided on a loan basis, can be collected by staff or members of the public. Simple items of equipment – bath boards and seats, raised toilet seats and surrounds can be collected after the submission of a 'requisition form'. Typically, 24 hours' notice is requested, however equipment required to facilitate timely hospital discharges or for those considered at the end of life are accommodated before this where possible. Technicians based on site deliver, fit and collect equipment including larger items such as portable hoists, hospital style beds and dynamic mattresses. Non-standard equipment (for example static seating, paediatric equipment and specialist rails) is accessed via a 'panel' of senior managers who either approve or decline submitted equipment requests. Panel members may request additional information before reaching a decision and there are opportunities to appeal when requests are declined. The local wheelchair service is based on site along with the podiatry laboratory.

Having considered the historical, national and local context of ADL equipment provision and occupational therapy the following section sets out the rationale for the present research.

#### 1.5 Rationale

From a professional perspective, within health and social care the drive for value for money continues to demand public services are delivered appropriately, effectively and in a timely manner. The need to quantify public spending, identify efficiency savings, and provide robust clinically based outcomes within the NHS and other organisations remains prominent in Department of Health documents (DH 2010a, DH 2010b) and the professional literature (Davis and Rodd 2014, RCOT 2019c). Additional factors impacting on available resources include a rise in societal expectations alongside an ageing population (Hocking 2004, Goodacre et al 2008, Pain and Pengelly 2010, Gillen and Watkins 2011). The result is an increased demand for equipment which can be expensive to purchase and maintain (Drummond et al 2012). Measuring the outcomes

of equipment provision is essential to enable the benefits and cost effectiveness to be established. This is of crucial interest to occupational therapists providing equipment and those who commission services (Chamberlain et al 2001). With this in mind, during its early stages this present research determined to focus on and examine occupational therapy based equipment provision and its use. The research question reflecting this was:

'What is the role of occupational therapists in equipment provision and the facilitation of its effective use?

However, as the research developed and evolved it soon became evident that this question in its then current form was too broad and likely to have failed to explore the deeper experience of equipment use and occupational therapy practice. To continue would have resulted in a set of findings unlikely to differ from that which had previously been published. This awareness combined with my personal and professional experiences outlined in Section 1.1 transformed the focus of the main research project into one which represented the actual voices of individuals with first-hand experience of the phenomena under study. As a result, the primary research question evolved in line with the background, rationale and author's perspective provided in Sections 1.2 through to and including Section 1.5. Furthermore, a robust search of the literature (Chapter 2) identified little evidence surrounding the actual use of equipment by those who use it within their home environment. The lack of research exploring the relationship between equipment, quality of life and independence has been highlighted by several authors, past and present including Smith (2009). This paucity of evidence attesting to the experiences of individuals, particularly within the UK, identified a clear need for research which sought to explore the voice of the user and those who assess for and provide equipment. The primary research question therefore developed into one representative of occupational therapy practice, equipment and its use. The objectives were developed in line with the primary research question to assist with drawing out and exploring in detail the topic under study.

#### 1.6 Principle Research Question

How do service users and occupational therapists in the United Kingdom experience equipment for activities of daily living?

#### 1.7 Objectives:

• To explore and critically examine the available body of literature surrounding equipment for daily living provision by occupational therapists.

- To interview individuals who use, assess for and provide equipment for activities of daily living.
- To interview clinical leaders or managers with responsibility for the outcomes of equipment for daily living activities assessed for and provided by occupational therapists.
- To critically analyse and interpret the findings from the qualitative interviews.
- To disseminate the information which emerges from this present research via the evidence base, occupational therapy and other equipment based services, stakeholders and educational establishments.

## 1.8 Summary of Thesis:

Having set out the background to the present research in Chapter 1, the rest of the thesis presents the detailed work of the project itself. Chapter 2 focuses on a systematic approach to identifying and reviewing the existing literature associated with occupational therapy UK based practice and ADL equipment. An argument is presented that despite the existence of a significant volume of equipment based literature, little of this supports the use or impact of ADL equipment provision. Chapter 3 provides the detail surrounding the selected methodology and methods used for the main research element of this project. This includes the introduction of interpretative phenomenological analysis as the premise to and foundation for the conducted research. Chapters 4, 5 and 6 present the findings and analysis of the data from the three participant sub-groups: the clinical leaders, occupational therapists and service users respectively. In Chapter 7 the findings are discussed in relation to the wider context of occupational therapy clinical practice and the literature. Where relevant the developing themes are compared and contrasted across the three sub-groups. Attention is given to the implications to occupational therapy practice, research related reflexivity, and the limitations of this research. Recommendations for future practice, education, and research are provided. The overall conclusions to this research project can be found in Chapter 8.

#### **Chapter 2: Occupational Therapy Equipment Provision: Reviewing the Literature**

Chapter two describes the in-depth systematic approach used to explore, identify, and review literature relating to the existing evidence base surrounding occupational therapy and equipment for activities of daily living within the United Kingdom. It reports the outcomes of this process and highlights the paucity of quality research available to support this area of clinical practice. The conclusion summarises the overall findings, supports the need for this present research and highlights the implications to practice and the potential for future research.

#### 2.1 Rationale

A rigorous approach to identifying and reviewing the literature, as defined by Grant and Booth (2009) was adopted. Of the 14 types of review offered by Grant and Booth (2009), this review of the literature most associated with the critical review and the systematized review. Both forms of these reviews include a comprehensive search of the evidence base, a robust analysis and synthesis process which does not include a meta-analysis or meta-synthesis aligned to a systematic review (Grant and Booth 2009, Higgins et al 2019). The approach adopted provided the opportunity to explore primary research evidence pertaining to occupational therapy equipment provision specifically designed for activities of daily living within the UK. Research purporting to investigate or explore the actual use of or impact of ADL equipment was included. The data collated from the included research papers is presented thematically. This followed a robust systematic process of sourcing, appraisal, and analysis of the literature. The review identified several questions and issues which would benefit from further exploration and link to the overall aims and objectives of this main research project.

## 2.2 Aims of the Literature Review

The aim of this review was therefore, to identify literature relevant to UK occupational therapy practice with a clear relationship between activities of daily living and equipment. The objectives explored the environmental and contextual elements of equipment assessment and provision and identified relevant policy and legislation surrounding equipment provision referred to within the included literature. The purposeful design of the search strategy, which placed no parameters on time, enabled the review to develop a historical perspective when exploring, for example, the types of equipment researched, and the participant groups involved. This perspective also provided the opportunity to explore past issues and concerns and, by comparing the

research papers, to establish whether they remain as pertinent today as they were in the past.

## 2.3 Searching for the Literature

Relevant literature was identified through the development of a search strategy based upon the intended outcomes of this systematic approach to reviewing the literature (Hickson 2008, Lou and Durando 2008, Beecroft et al 2015) and following advice from an academic liaison librarian. Key words or phrases associated with the concepts of occupational therapy, equipment, aids, assistive devices, or technology were explored. Boolean operators and truncation marks were applied to combine concepts and to enable variations of words to be recognised (Beecroft et al 2015, Booth et al 2015). The identification of relevant literature was refined through search parameters (Beecroft et al 2015), including literature published in the English language, narrowed by subject and key word searching of the title and abstracts. By narrowing the search by subject, it was possible to remove papers with key words identified as not relevant such as driving, home care services, orthotic devices, prosthesis, computers, and robotics. This parameter was applied when it became evident during the screening process that papers related to these subjects did not meet the inclusion criteria. As the review intended to compare the past with the present, a time parameter was not employed; the dates, therefore, presented in Figure 2.1 correlate with the availability of literature from the specific databases: AMED; CINAHL; MEDLINE; APA PsycINFO (previously PsycINFO). These four electronic databases were selected due to their association with health and social care allied health professionals, including occupational therapy.

The content of two primary journals, available electronically, were hand searched (Booth et al 2016, Aveyard 2019) to reduce the possibility of inadvertent exclusions. This process involved the systematic screening of each title included in all volumes and issues of the two journals: the British Journal of Occupational Therapy (BJOT) [from June 1938 to March 2020]; and Disability and Rehabilitation: Assistive Technology [from 2006 to March 2020]. Historically, the BJOT was known as the Journal of the Occupational Therapists' Association, Journal of the Association of Occupational Therapists and Occupational Therapy. As this literature review and research overall is focussed on the United Kingdom, the decision to hand search the BJOT was made.

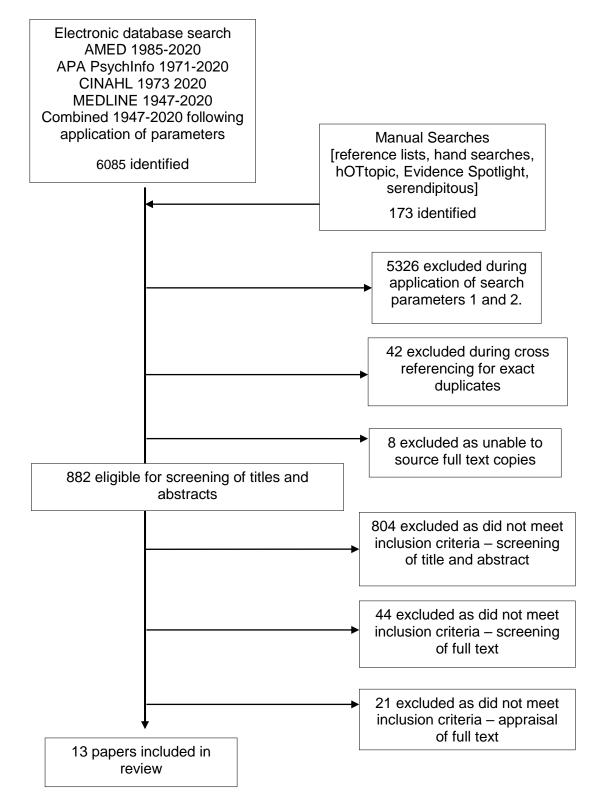


Figure 2.1: Search strategy strings and key words

Adapted from Moher et al (2009)

Equally, the focus of technology including equipment for ADL within the Disability and Rehabilitation: Assistive Technology journal made this a natural choice for enhancing the overall search strategy. This journal was founded in 2006. Prior to this, articles

would have been included in the Disability and Rehabilitation Journal (established in 1992), the journal of International Rehabilitation Medicine (1978 to 1986), or the journal of International Disabilities Studies (1987 to 1991). All issues up to and including December 2005 were hand searched.

A search of the library resources provided by the COT, identified two documents [hOTopic] listing a range of papers identified by them as relevant to the topic of assistive technology (COT 2012a, COT 2012b). More recently, a repeat of this specific search identified an 'Evidence Spotlight' produced by the RCOT (2020b) related to technology.

In addition, a concurrent search of Google Scholar was undertaken using the search string "occupational therapy" and "equipment" or "aid" or "assistive devices" or "assistive technology". The prospective papers were 'sorted by relevance' before the first 150 titles were screened for any relevant literature not identified during the electronic database search as described above. The use of the 'sort by relevance' tag elevated papers likely to be most applicable to the top of the list.

Whilst the process of screening identified several papers not included in the electronic data base search, these were found within the first few listed. It was therefore considered unnecessary to search beyond the first 150 papers. The overall search was further enhanced by the process of reference checking (Booth et al 2016, Aveyard 2019) the included papers identified as relevant, after applying the inclusion and exclusion criteria. This process followed the concept of snowballing (Booth et al 2016) which did have the effect of highlighting papers not obtained by the electronic database search. Papers highlighted serendipitously were also examined for relevance. The overall results of the electronic database, journal, hand and reference checks are provided in Table 2.1. Throughout the course of this research, the electronic database searches outlined above have been repeated periodically to ensure currency of the information sourced; the last search took place in October 2020.

## 2.4 Inclusion and Exclusion Criteria

The development of inclusion and exclusion criteria (Table 2.2) enabled the literature sourced through the data collection method to be screened for relevance (Neuman 2014, Aveyard 2019). Due to a research focus on occupational therapy and therapist practice related to equipment provision in the UK, the decision to exclude international literature was made where a clear separation of the data was not provided. For example if there was no distinction between the geographical origin of the data or the

profession/s involved. This decision was based on the potential bias which may have arisen due to variances in funding, as well as access to, and delivery of, health and social care services (Rogers and Holm 1992). In hindsight, as discussed later in section 2.9 this decision may have been premature as the inclusion of international literature may have enhanced the overall findings of this review. Included literature clearly referred to portable equipment or that which required minimal structural fixing such as grab rails and handrails, assessed for by occupational therapists within the UK, and used within the home environment. Literature where equipment provision was not the primary research aim or question but was clearly included as an objective outcome were accepted if other criteria were also met. In addition, the definition of an ADL as outlined in Section 1.2.3 was used during the process of inclusion and exclusion. Despite the potential for publication bias, the decision to exclude grey literature from this systematic approach whilst reviewing the literature was made. Grey literature is typically described as 'unpublished' and may include local policy, dissertations and journals considered as non-academic (Aveyard 2019, Booth et al 2016). As the focus of this literature review was to explore the existing evidence base, peer reviewed research freely available in the public domain was considered the most appropriate content. Where for example dissertations were identified during the literature search, attempts were made to locate a later published version of the research. Equally, other forms of grey literature (such as Governmental, other organisations and key website publications) are included within the report as appropriate.

As demonstrated in Figure 2.1, a combined total of 6085 references were obtained via the electronic database search (AMED, APA PsycINFO, CINAHL and MEDLINE). After the application of the two search parameters this number reduced to 759 and 717 after cross referencing for exact duplicates. Manual searches identified a further 173 potentially relevant papers resulting in an overall total of 890. Despite attempts, the full text copy of eight papers or texts have not been sourced. These are: Hunt (1978), Robertson and Haines (1978), Keeble (1979), Ward (1979), Shopland et al (1979), Anderson (1984), Campbell (1991), Mountain (2000). Of the remaining 882, 804 papers were excluded as they failed to meet the inclusion criteria [Table 2.1] when applied to the title and abstract. Of these, a further 65 were excluded following the process of screening, or during a primary appraisal of the full text. The relevance of the eight un-obtained documents remains unknown. This process left a total of 13 papers for critical appraisal and inclusion in the review.

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# 2.5 Exclusions

A total of 869 papers were excluded from this literature review. A small selection of these are detailed below to demonstrate their relationship to equipment for activities of daily living and to offer an explanation of their exclusion particularly as they were identified as part of the literature search process.

Inclusion	Exclusion
<ul> <li>i. equipment referred to was clearly assessed for by occupational therapists</li> </ul>	<ul> <li>i. literature reviewing the effectiveness of services</li> </ul>
ii. participants reside in the UK	<ul> <li>equipment is an unintentional/tangential outcome of the research findings</li> </ul>
iii. research relates to clinical practice in the UK	iii. medical devices including telehealth/ telemedicine
<ul> <li>iv. ADL equipment informs the research question or intended objectives / outcomes (including questionnaire/s)</li> </ul>	<ul> <li>iv. electronic/computer based assistive technology</li> </ul>
v. ADL equipment used within the home environment	v. product description/ design/ development
vi. Portable, minimal fixing and/ or removable ADL equipment within the home environment	vi. major structural works, for example: ramps/ extensions/ wet rooms
	vii. grey literature

## Table 2.1: Inclusion and exclusion criteria

## 2.5.1 Assessing Professions: a lack of clarity

As demonstrated in Sections 2.5.1.1 and 2.5.1.2 a large proportion of the papers excluded were found to not explicitly identify which profession was responsible for the assessment of the ADL equipment investigated in the research conducted.

## 2.5.1.1 Occupational therapists

As previously detailed in Section 1.2.2, within occupational therapy and therapy services generally there is a distinct range of roles. The following papers which met a number of the inclusion criteria were excluded as they were either insufficiently clear about who provided the equipment or indicated the assessment was completed by a non-qualified member of the team. As the focus of this literature review and research overall is on occupational therapists, whilst it is recognised the papers are relevant to

equipment and ADLs, as such, they do not meet point one of the inclusion criteria. Examples of some of the papers excluded are, Chamberlain et al (2001) who despite initially indicating assessment and provision by occupational therapists then later referenced input by occupational therapy assistants as part of the assessment process. The audit, conducted by telephone, investigated equipment remaining in use over a period of 18 months to two years post provision. In addition, it explored frequency of use, assistance from others and usefulness. A copy of the audit is provided within the paper. Similarly, a study which explored the use of equipment following a total knee replacement (TKR) (McNaught and Paul 2015), initially indicated the researcher, an occupational therapist, completed the three component assessments. However, later in the paper, this altered to the mid-assessment having been completed by a support worker. The findings of McNaught and Paul's (2015) research supported the need for post-surgical assessment to identify individual need whilst also stressing the importance of a period of rehabilitation and review to prevent over dependency. In support, McNaught and Paul (2015) highlighted how the long-term use of the equipment provided during the course of their research may have remained in use far beyond that deemed necessary, thereby reducing function and creating a reliance on the equipment provided.

A survey conducted by Goldthorpe and Lloyd (1993) sought data from 505 older patients registered with one GP practice. Of the 410 individuals approached, 336 returned their questionnaire. The survey identified unmet need and the lack of understanding surrounding the occupational therapy role within the community. They recognised a significant discrepancy between the met and unmet need of the older population under study and the potential impact on resources should occupational therapy referrals increase. They highlighted how the provision of equipment for activities of daily living may reduce the need for residential care by maintaining independence levels within the home environment. Unfortunately, Goldthorpe and Lloyd (1993) did not specify which team members were responsible for the assessment of the equipment listed in the questionnaire, a copy of which is provided in the published article.

#### 2.5.1.2 Other professions

Examples where the profession or professions are unknown include Humphreys et al's (2019) systematic review exploring the use of night-time positioning equipment and a project exploring the provision and use of equipment for individuals with a diagnosis of rheumatoid arthritis (Hollings and Haworth 1978). Whilst Hollings and Haworth (1978) referenced occupational therapy within their paper the assessment and provision of

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equipment is not distinguished between other professions or a distinct service. Similarly, it was unclear in Dewey's (2004) qualitative research project exploring the use of tilt-in-space and conventional wheelchairs, which therapy profession completed the assessment process. Sainty et al (2009) used a survey to explore the long-term use of equipment in the community. They were interested in what equipment remained in use, and its impact on the lives of the recipients and satisfaction levels. The specific domains they explored were dignity, QOL, choice, and control. Service satisfaction levels were also examined. The equipment investigated was assessed for and provided by a range of health care professionals and services. Although the report indicated the percentage of participants who had received equipment via the occupational therapy service, this was not further itemised. With regard to the three domains, 172/251 respondents reported improved choice and control, 198/251 a positive impact on the QOL and 117/251 indicated an increased sense of dignity and respect. Written comments were also provided by the respondents, these reflected the impact equipment had on function rather than emotional well-being. An increased sense of safety was reported in both the choice and control, and QOL domains. A decrease in dependency correlated with an increase in feelings of self-esteem and dignity. Overall, Sainty et al (2009) concluded equipment provided for use, and is in-use, in the community did have positive benefits and outcomes. They also advocated the benefits of seeking a mixture of both qualitative and quantitative data to inform the evidence base and commissioners of services.

According to Galer and Feeney (1979), a survey undertaken in 1974 on behalf of the Department for Health and Social Security (DHSC) identified the number of feeding and personal care equipment items most likely to be issued by social services departments. They were found to provide the highest volume of equipment, however other agencies including the Red Cross and Area Health Authorities issued equipment in considerable numbers. Social services departments would have consisted of a range of professions, of which many may have issued equipment as part of their role. Galer and Feeney (1979) highlighted the disparity and overlap between the types of equipment provided by the various health and social care organisations.

Similarly, Atkinson and Andrews (1980) outlined the older adult equipment-based responsibilities of social service departments, area health authorities and others such as general practitioners and consultants. They highlighted a clear divide between social service and health authorities. The return of equipment, joint stores and charging for equipment was also referred to. The growth of equipment available was linked to the implementation of the Chronically Sick and Disabled Persons Act 1970 (Great Britain.

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Parliament 1970). Atkinson and Andrews (1980) did however suggest the variety of equipment styles made available through statutory provision was limited due to the need to purchase high numbers of the same design to reduce costs.

## 2.5.2 International origins

Papers excluded with an international origin included Wielandt et al (2006), Krantz (2012), and Meyer Larsen et al (2019). The research involved the long-term use of equipment post-discharge, the utilisation of equipment in everyday life, and the perspectives of becoming a user of equipment respectively. Whereas a review of the literature conducted by Wynn and Wickham (2009) neither distinguished between the geographic origins of the papers they included in their review nor between the professions of those assessing or supplying the equipment to which they referred.

#### 2.5.3 Equipment as an unintended finding or relationship

Despite referring to the occupational therapy profession, the primary research aims, objectives or outcomes of a small number of papers did not include ADL equipment. Taylor (2011), who completed a qualitative research project, found the topic of sexuality and intimacy was not addressed by health professionals, including occupational therapists, when providing hospital style beds to individuals with motor neurone disease. Meek et al (2010), reported on the feasibility and outcome of the design of a randomised controlled trial based on the development of an occupational therapy Parkinson's disease intervention (OTPD intervention) designed to improve occupational performance. Though the subject of equipment was present, this was in respect of the authors determining the number of times this was the principal purpose of any intervention taking place during the research. They found equipment or changes to the physical environment occurred primarily in 94 of the 274 interventions which took place; no further details were offered. A survey consisting of 36 questions, conducted by Jones et al (2007) explored current occupational therapy based paediatric practice. Similarly, to Meek et al (2010), Jones et al's (2007) survey focused on, amongst others, the number of referrals and interventions related to equipment that were recorded or reported on by the respondent occupational therapists. As such, the survey was concerned with paediatric practice overall rather than with a particular emphasis on equipment-based interventions. McQueen et al (2009) explored occupational therapy practice in relation to hip precaution interventions following a hemiarthroplasty. Of the 10 questions in the survey, one asked whether a standard equipment pack was issued and if so, which equipment was included. The focus of the survey centred on the advice and information given to prevent dislocation of the hip joint.

#### 2.5.4 Community use and others

During the screening process numerous papers were found to involve ADL equipment prescribed for particular use within the community. For example, the focus of Benford's (2017) report was a case study practice analysis based on outdoor powered wheelchair mobility rather than ADL use within the home environment. Similarly, the use of powered wheelchairs on occupation was the emphasis of Evans' (2000) research. Whereas other papers focused on medical devices and electronics. Examples include, McGrath et al (2017) who centred on occupational therapists' choice and selection of electronic technology in general rather than the more traditional types of ADL equipment. Medical devices related to sleep hygiene were the focus of Biajar et al's (2017) literature review. Several papers involved research related to the use of robotics, examples include articles by Campbell (1986) and Rahman et al (2012).

#### 2.5.5 Service development and reviews

A report by White and Lemmer (1998), outlined the findings of a five year review of the effectiveness of a remodelled wheelchair service. As the focus of their research centred on service remodelling, White and Lemmer (1998) did not indicate which professions were responsible for the assessment of the wheelchairs referred to in their report. A survey published in 1980 (Stowe and Chamberlain) explored the equipment available for direct purchase from the British Rheumatism Association Catalogue. It was interested in whether the range of equipment available was sufficient or useful and to explore the long-term viability of the service. Brittle et al (2007) provided a profile of equipment users in relation to their age, dependency levels and which functional areas were problematic, for example, dressing and bathing. Similarly, Swinson et al (2016) who also used a survey, explored occupational therapy practice in the UK, while Forsyth and Hamilton (2008) examined the integration of health and social care services. These papers were excluded as their focus was on the service itself rather than the equipment provided. Armstrong (2001) investigated whether one of several standardised outcome measures could be implemented into their clinical practice. The report described the development and implementation of a service specific measure but does not refer to the equipment provided by the occupational therapists within a social service environment.

## 2.5.6 In summary

All of the articles cited above were identified via the search strategy adopted for this literature review. They were excluded as they were unclear in outlining a direct relationship between occupational therapists and equipment for activities of daily living within the home environment and/or the UK.

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# 2.6 Inclusions: Appraisal and Data Extraction

As highlighted in Section 2.4, a total of 13 research papers were included in this review of the literature. However, due to multiple publications the 13 papers were found to represent nine research studies. Overall, seven of the 13 papers reported on three of the projects. The relationship between the seven papers and three corresponding projects are provided in Table 2.2 below.

		<b>-</b>			
Study	Reference	Study Title			
Study 1a	Thornely, Chamberlain, Wright (1977)	Evaluation of aids and equipment for the bath and toilet.			
Study 1b	Chamberlain (1979)	Aids and appliances in the home – a critical survey of bath aids and their use.			
Study 2a Stowe (1979)		AIDS – who uses them?			
Chamberlain, Study 2b Thornley, Stowe, Wright (1981)		Evaluation of aids and equipment for the bath: II. A possible solution to the problem.			
Study 2c	Stowe, Thornely, Chamberlain, Wright (1982)	Evaluation of aids and equipment for bathing: survey II			
Study 3	Haworth and Hopkins (1980)	Use of aids following total hip replacement.			
Study 4a	Beattie and Caird (1980)	The occupational therapist and the patient with Parkinson's disease.			
Study 4b	Beattie (1981)	Aids to daily living for the patient with Parkinson's disease.			
Study 5	Milne (1988)	Bathing aids for handicapped children.			
Study 6	Hart, Bowling, Ellis, Silman (1990)	Locomotor disability in very elderly people: value of a programme for screening and provision of aids for daily living.			
Study 7	Davidson (1999)	Total hip replacement: an audit of the provision and use of equipment.			
Study 8	Goodacre and Turner (2005)	An investigation of the effectiveness of the Quebec User Evaluation of Satisfaction with Assistive Technology via a postal survey.			
Study 9	McNaught, Jones, Immins, Wainwright (2016)	Patient-reported importance of assistive devices in hip and knee replacement Enhanced Recovery after Surgery (ERAS) pathways.			

# Table 2.2: Papers included in the review

The decision to collate the corresponding published papers into tables which represent the nine individual studies, rather than chronologically as may be expected, was made to improve the flow of the text within subsequent sections. As such, from this point forward, the studies are referred to by an assigned study number (Study 1 to 9) in place of their citation/s. Where reference is made to a single paper within a grouped study, these studies have been further labelled as Study 1a and b, Study 2a, b and c and Study 4a and b. Tables 2.4 to 2.12 in Section 2.6.4 contain information extracted from the 13 papers.

## 2.6.1 Purpose and focus of the critically evaluated papers

The nine studies explored a similar range of ADL related equipment issues designed to inform the intended outcomes of their research; these are summarised below.

One hundred and fifty participants in Study 1 evaluated bathing and toileting equipment via a face-to-face survey completed between six and 24 months post hospital discharge. The research investigated the prescription, supply and long-term use of equipment assessed for by inpatient occupational therapists from indeterminate specialities. Associated factors included the environment, assistance from others, the durability of equipment, delivery times and safety concerns. Study 2, a follow-up randomised control trial (RCT) developed from the findings of Study 1, explored whether the timely provision of equipment combined with enhanced instruction and 'inhouse' demonstrations improved the overall use, patient satisfaction and occupational performance levels of the 100 participants. Whilst Study 2 purported to have explored bathing and toilet equipment, it reported only on that related to bathing. As a follow-up to Study 1, similar information was sought from the participants.

Study 3 explored the use of mobility, bathing, toileting, and dressing equipment with participants following surgery for a total hip replacement (THR). The participants were approached on three separate occasions, face to face on admission to hospital (with 150 participants) and at nine months post discharge (144 participants) and once at three months via a postal questionnaire (131 respondents). The participants provided information related to any equipment in the home environment, whether it was in use at each contact point and if any had been returned. The four main types of equipment were identified as walking, bathing, toileting, and dressing.

Research involving 81 patients with Parkinson's disease explored whether occupational therapy assessment combined with equipment provision enhanced disease management (Study 4). The participants were visited by an occupational

therapist on two occasions. During the first visit, participants were classified as being either not disabled (able to live independently), disabled (able to live at home but not requiring assistance with personal care), or dependent (required assistance with selfcare). The second visit identified whether the participants classifications had altered. Any equipment identified as relevant at the point of assessment, though not in-situ, was provided. As with the previous three studies, bathing, feeding and toileting equipment dominated the research. The emphasis was on factors such as changes in condition and the volume of equipment required, its usefulness and utility.

Study 5 reported on the outcome of a Department for Health and Social Security Disability Equipment Assessment Programme aimed specifically at children. A questionnaire forwarded to paediatric occupational therapists verified the most common types of bathing equipment issued in the community at that time. Other items of paediatric bathing equipment were explored and identified by the researcher, some of which were subsequently included in the practical element of the research. Checklists completed by the 28 participants or their care givers investigated frequency of use, acceptance, aesthetics, and design amongst others.

Study 6 explored the number of older residents in one London Borough who may have benefitted functionally from the provision of simple items of daily living equipment. Five purposefully selected items were used as the basis for this RCT; raised toilet seats (RTS), teapot tippers, double handled lightweight saucepans, tap turners, and long handled shoehorns (LHSH). The population studied consisted of participants over the age of 85 years. Of the 744 potential participants, 130 were assigned to either the control or intervention groups. The participants in the intervention group were issued with equipment at the initial assessment stage whereas those assigned to the control group received theirs later (after four weeks). A second visit to review function, completed at the four week stage, identified any changes in functional ability. In addition to investigating the changes in functional ability, the process identified the volume of unmet need and facilitated calculation of the cost benefit of equipment provision.

Study 7 explored the withdrawal of funding for 'hip packs' in a specific NHS Trust. The affected NHS Trust conducted a postal questionnaire to audit the level of provision and use of equipment post THR surgery (Study 7). In addition to factors previously examined in Study 3, this study of 63 respondents investigated the concept of patient's privately purchasing equipment. The focus here was on toileting and dressing equipment.

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0) was used to explore the long-term outcomes of equipment provision, specifically with individuals in receipt of a stairlift (Study 8). The QUEST 2.0, designed to evaluate satisfaction levels, was returned by 55 respondents. An additional questionnaire gathered demographic information and information related to the impact of provision on quality of life.

Joint replacement (hip and knee) surgery formed the basis of Study 9 which investigated patient-reported levels of importance in relation to the equipment provided. The service evaluation contacted patients by telephone two weeks post-discharge, of which 114 consented to complete the questionnaire. The questionnaire was interested in topics such as: the usefulness of the advice and information provided, whether the equipment remained in use and if there had been any impact on the participants ADLs. Participants were also asked if, in their opinion, the equipment had facilitated a timelier discharge.

## 2.6.2 Hierarchy of evidence

Due to the preferences of previous academic supervisors, past and present postgraduate studies have included discussion surrounding the concept of a 'hierarchy of evidence'. As a result the same consideration was afforded to the concept during the early planning of this review of the literature. However as demonstrated during the remainder of this section, the usefulness of an evidence hierarchy was explored and subsequently dismissed.

The use and importance of criteria to determine the quality of research studies is discussed extensively in the literature by for example Booth et al (2015) and Rees et al (2015). The process of determining quality typically explores issues such as the validity, reliability and applicability of the research (Rees et al 2015), the outcome of which assists with the identification of effective interventions within for example clinical practice. The higher the degree of quality in the robustness of the research is indicative of the confidence clinicians may have in implementing its findings into their own practice (Rees et al 2015). There are several tools or checklists available to assist the reviewer with this process.

Traditionally, hierarchy's of evidence place meta-analyses and systematic reviews at the top, closely followed by RCTs (Greenhalgh 2014, Aveyard 2019). Toward the bottom of the pyramid are cohort studies, surveys, and case reports with qualitative studies often not included (Greenhalgh 2014). A few papers highlighted the elevated,

yet to some questionable, status of RCT, for example Sackett et al (1996), compared to the position qualitative research finds itself in within the evidence base (Diaz Crescitelli 2019). The Centre for Evidence Based Practice (CEBM) provided an example of the process (2009). The literature posits that RCTs are not necessarily the most effective method of exploring outcomes, rather alternatives most relevant to the research should be selected and used (Booth et al 2016, Aveyard 2019). Literature purporting to provide a tool for positioning qualitative research into an evidence hierarchy was identified (Daly et al 2007). However, its approach placed qualitative based literature into four categories ranging from single case studies (level four – the bottom) to those considered as generalizable (level one – the top). Daly et al's (2007) hierarchy was not selected as little attention appeared to be given to the overall quality and conduct of the research. In addition to these factors, a single case study was simply designated as lower level research and the use of the term generalisable as opposed to transferability was also questionable.

Given the structure of hierarchy of evidence tools, the use of this method to determine the quality of any research papers was considered inappropriate to this review of the literature. The rationale for this was based on the idea that the quality of the evidence being sought involved the topics of ADL equipment, occupational therapy, their practice, and the service user's use of the equipment. As such, the emphasis on the method of data collection as the exclusive factor to indicate inclusion to the review was considered less germane in comparison to the overall quality and findings of the research being appraised irrelevant of its methodology and methods. The overall quality of the research was considered important, rather than the nature of the data collection and did not therefore form part of the inclusion or exclusion criteria.

In hindsight, had a traditional hierarchy of evidence been applied to this literature review, most of the papers as a consequence of their design, would have been excluded. Additionally, given the overall quality of the two papers identified as RCTs (see Section 2.6.3 below), both Stowe (1979) and Hart et al (1990) are likely to have been excluded. As such, the strict application of this type of hierarchy of evidence would have resulted in the exclusion of all 13 papers. As the importance of seeking a method of appraising published research is known, an alternative method of quality appraisal was therefore sought as outlined in the following section (2.6.3).

## 2.6.3 Appraising and grading the papers

An appraisal process designed to examine the subject content and quality of the included papers was adopted. The appraisal tools selected were the Critical Review

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Form – Quantitative Studies (Law et al 1998a) and the Critical Appraisal Form – Qualitative Studies (Version 2.0) (Letts et al 2007a). The decision to use these tools was based on the experience of past use and further supported by companion guidelines (Law et al 1998b, Letts et al 2007a, Law and MacDermid 2008). Rather than placing the included research papers into a hierarchy of evidence, as outlined in Section 2.6.2, the decision to rate evidence quality and explore the relevance of recommendations was made. The principles of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) tool (Guyatt et al 2008, Guyatt et al 2011, Schunemann et al 2013) was adopted to demonstrate the quality of the evidence and the strength of any recommendations made by each of the included research papers. Table 2.3 demonstrates the modelling of the grading applied.

The intended purpose of the two critical review forms and the GRADE tool was to assist with the process of appraisal and to extract relevant data associated with the review. They were not intended as a method to censure and exclude papers (Steward 2006, Booth et al 2016, Carter and Lubinsky 2016). They were used to explore the information related to ethics and the methods provided as a means of being aware of potential research limitations or bias. The decision to include papers not based on their quality was also discussed by Boland et al (2017).

The quality and relevance of grading along with key data extracted during the critical appraisal process can be found in Tables 2.4 to 2.12 in Section 2.6.4 and Table 2.13 in Section 2.7.2.

## 2.6.4 Data Extraction

Key information from the critical appraisal process relevant to the aims given in Section 2.2 of this review are collated in Tables 2.4 to 2.12 and Table 2.13. Data Extraction Tables 2.4, 2.5 and 2.7 represent the three studies with multiple publications, Tables 2.6 and 2.8 through to and including 2.12 represent the six other studies. These tables capture information related to the equipment referred to, areas of enquiry, any equipment related conclusions and recommendations highlighted by the authors. The final column indicates the GRADE score. Where multiple papers represent the same research, data from the earliest publication is extracted in detail. Additional data only is included from the subsequent papers in chronological order [oldest first].

Qua	Quality of Evidence			th of recommendations
Quality Description			Strength	Description
High-A	All factors included with full explanations provided. Appropriate and accurate use/presentation of all statistical data		Strong-1	All or the majority of factors are attended to in any detail
Moderate-B	Majority of factors included with majority of explanations provided. Appropriate and accurate use/presentation of the majority of any statistical data			
Low-C	Some factors included with some explanations provided. Appropriate and accurate use/presentation of some of the statistical data		Weak-2	A minority of the factors are attended to in any detail
Very Low-D	Few factors included with little or no explanations provided. Poor use/presentation of the statistical data			
<b>Factors</b> : Intended outcomes, literature explored, provides number of participants and justification, methodology (including design, drop outs), ethics, findings,			outcomes, from the	tations, reflects/relevant to outcomes have developed research (clearly stated), as to practice, realistic

**Table 2.3**: Quality of evidence and strength of recommendations

Adapted from (Guyatt et al 2008, Guyatt et al 2011, Schunemann et al 2013).

As initially indicated in Chapter 1, Section 1.5, the findings of this in-depth review of the literature identified little published research relating to the use of ADL equipment within the home environment and which had been assessed for by an occupational therapist. Information relevant to the papers aims and objectives, methodology and methods and the sample groups are presented in Sections 2.7.1 to 2.7.3.

	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
Study 1	<b>Study 1a</b> Thornely, Chamberlain, Wright (1977)	Bath boards Bath seats Bath mats Over tap rails Grab rails Commodes Chemical commodes RTS Free standing/floor fixed toilet surrounds Miscellaneous including alternatives for night use Wall fixed rails	Survey: Environment Help available Use made of the bath/toilet Items prescribed Items supplied and used Delivery times Durability Accidents Characteristics: design, confidence, comfort, dignity, consequences	<ul> <li>Highlights various environmental factors which affect provision and use of equipment (18% not able to bath and 6% occasionally)</li> <li>Highlights issues with equipment design</li> <li>Highlights issues with acceptable delivery times</li> <li>Highlights role of others in supporting access to/use of equipment</li> <li>325 bath boards/seats/mats/tap rails provided – 68% of these in use</li> </ul>	D2
	<b>Study 1b</b> Chamberlain (1979)	Paper limited to bathing only Clarifies grab rails above Bath board prescription rose to 81%, use to 95%, all participants in the treated group now bathing	Questionnaire: Bathing environment The bath Function of bathing Assistance Activity of washing Characteristics: design, reliability, accident rates, delivery, instruction, follow-up	<ul> <li>8% bathed occasionally</li> <li>Environment [built and Ax areas] major factor in suitability of equipment</li> <li>Need more thorough instruction by OTs</li> <li>Highlights importance of bathing aids to maintain some independence</li> <li>Highlights issues with architectural design</li> <li>Highlights impact of delay in provision</li> <li>Highlights need for timely assessment</li> </ul>	D2

 Table 2.4: Study 1 – Data extraction: summary of appraised article

Table 2.5: Study 2 – Data	extraction: summar	y of appraised article
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	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
12	Study 2a Stowe (1979)	Initially refers to Thornely et al (1977) Bathing Toileting Rails	Initial: Biographical data Equipment ordered Assistance required and by whom Functional ability Characteristics: mobility, level of independence, assistance required, equipment in use Then: functional levels, facilities, assistance required, equipment used – satisfaction, timely delivery, confidence levels	<ul> <li>100% of TG bathing compared to 80% of CG</li> <li>TG bathed more confidently, frequently and safely</li> <li>TG required more equipment</li> <li>COT<sup>2</sup> liaising between HOT and SSOT beneficial</li> <li>Able to resolve minor issues with equipment quickly</li> <li>Suggests investing time in follow-up is beneficial</li> </ul>	D2
Study	<b>Study 2b</b> Chamberlain, Thornley, Stowe, Wright (1981)	Bathing (149TG) Bathing (121CG) Bath seats Bath boards Mats Rails	Themes: Environmental factors Numbers bathing Supply and use Waiting times Unsatisfactory equipment	<ul> <li>Bath aids – overall usage 80%</li> <li>All able to reach bathrooms unlike Study1</li> <li>Correct items received in timely manner</li> <li>Further instruction in own environment</li> <li>Needs investment of time for OT but less for others i.e. social workers and nurses</li> <li>Less non-use of equipment</li> <li>Use of equipment to negotiate bath sides safer than standing</li> </ul>	D2
	<b>Study 2c</b> Stowe, Thornely, Chamberlain, Wright (1982)	Bath boards Bath seats Bath mats	Characteristics: disease, function, stability, disability, environment, delivery times, safety, asked to demonstrate use	<ul> <li>Highlights value of in-house teaching/demonstrations</li> <li>Review and retrieval process</li> </ul>	D2

 •, •, •				
Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	
Haworth and Hopkins	Walking Bathing	Number of equipment items on site	wledge quicker waiting times for surgery than centres so level of disability may be less	

Table 2.6: Study 3 – Data extraction	n: summary of appraised article
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Study 3

Hopkins	Bathing	on site		other centres so level of disability may be less
	Toilet	Use of equipment over time	0	None use most evident with UOA
(1980)	Dressing	Equipment returned	0	Largest discrepancy between possession and use
		Other		with dressing equipment
	Other items not		0	Identifies need for timely supply and retrieval process
	included in analysis		0	Highlights issues with equipment provision for short
				term need
			0	Further research for equipment use within 3 month post-operate period
			0	Explore need longer term provision of equipment post recovery period

GRADE

D2

	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
Study 4	<b>Study 4a</b> Beattie and Caird (1980)	Bathing Feeding Toileting Miscellaneous	Changes in condition Usefulness Greater need Additional need	<ul> <li>Several participants indicated no need for an OT visit = biased participant group toward those with a disability?</li> <li>Implies those with PD do not have the equipment they require [even following an OT visit 7/29 had all equipment required]</li> <li>Majority of equipment considered valuable by the users</li> <li>Cost of equipment equalled that of 26 days of levodopa</li> <li>Ax at home by OTs: is beneficial, part of routine management, small aids are helpful, contribution considerable</li> <li>Identifies need for follow up/ reviews</li> <li>Identifies little published evidence of OT and PD</li> </ul>	D2
	<b>Study 4b</b> Beattie (1981)	Bath mat/s Bath rail/s Bath seats/boards Toilet frames/ rails / RTS	Number of participants requiring equipment Usefulness Utility	<ul> <li>OT assessment of great benefit</li> <li>Should be part of routine management</li> <li>Cost of equipment low</li> </ul>	D2

 Table 2.7: Study 4 – Data extraction: summary of appraised article

	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
Study 5	Milne (1988)	Bath seats Supports Inserts	Frequency of use Usability/non-use Acceptance levels Aesthetics Utility Comfort Design Multipurpose use	<ul> <li>Highlights lack of evidence</li> <li>Highlights importance of considering practical and quality factors related to bathing</li> <li>Effective support reduces strain on parent / carer, the child feels more secure and can enjoy their baths, may result in more baths</li> </ul>	D2

 Table 2.8: Study 5 – Data extraction: summary of appraised article

**Table 2.9**: Study 6 – Data extraction: summary of appraised article

	Reference	Equipment Referred To	Areas of Enquiry		Equipment related conclusions and recommendations	GRADE
Study 6	Hart, Bowling, Ellis, Silman (1990)	RTS Teapot tipper Saucepans Tap turners LHSH	Prevalence of poor locomotor function Reversibility following provision of equipment Relative cost of assessment and provision	0000	Reflects only those living at home with some level of independence – not the population as a whole Results support early assessment and provision improves functional outcomes in the very elderly Found modest financial implications Highlights unknown degree of disability in one population – in this case 22% – and who may benefit from an intervention	D2

	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
Study 7	Davidson (1999)	RTS Easi-reachers LHSH Sock/ tights aid	Number of items provided Usefulness Recommended time use Still in use Popularity Utility Private purchasing	<ul> <li>Majority of participants found equipment useful/ positive feedback</li> <li>Equipment generally helpful and some remaining in use</li> <li>Used for recommended period of time</li> <li>Participants adhere to therapists recommendations</li> <li>93% (51/55) would purchase one item [after seeing the advantages]</li> <li>High number of patients used equipment for recommended period</li> <li>Offers ideas for future research</li> <li>Several patients indicated they would have found the equipment useful before surgery</li> <li>Evidence supported ongoing provision resulting in loan/ recall services</li> </ul>	C2

 Table 2.10:
 Study 7 – Data extraction: summary of appraised article

	Reference	Equipment Referred To	Areas of Enquiry	Equipment related conclusions and recommendations	GRADE
Study 8	Goodacre and Turner (2005)	Stairlifts	Equipment used by Satisfaction levels Independence Quality of life Health benefits Dependency levels Ease of use Safety Effectiveness	<ul> <li>Reports general satisfaction with stairlift</li> <li>Least satisfaction with waiting times for provision</li> <li>Positive impact on QOL</li> <li>Services users responded well when asked for their views</li> <li>QUEST useful for providing outcomes data such as satisfaction, what works and which is best, most effective face to face but posting is acceptable, telephone based approach an alternative option</li> <li>Information can be used to inform purchasing of items and service improvement</li> </ul>	B2

Table 2.11: Study 8 – Data extraction: summary of appraised article

 Table 2.12:
 Study 9 – Data extraction: summary of appraised article

	Reference	Equipment Areas of Enquiry Referred To		Equipment related conclusions and recommendations		
Study 9	McNaught, Jones, Immins, Wainwright (2016)	LHSH Easi-reach Sock aid RTS Bed / chair raisers	Education/advice Equipment in use Impact on ADLs Impact on discharge	<ul> <li>Advice and equipment provided by OTs is useful</li> <li>Those with invasive surgery use equipment for longer</li> <li>2 week follow-up may encourage return to function</li> <li>Longer term use may be due to co-morbidities</li> <li>Suggests equipment plays positive role in timelier discharges</li> <li>Acknowledge some participants may have stated still using equipment to appear to be adhering to recommendations post- surgery [12 weeks for PTHR]</li> <li>Suggests caution to removing hip precautions [such as equipment provision] as more evidence needed</li> </ul>	B2	

## 2.7 Findings

Section 2.7.1 to and including 2.7.4 reports on the methods and methodologies adopted by the researchers, the methodological quality, the participants, and the equipment referred to. Section 2.7.5 provides an overview of the thematic coding and analysis process.

## 2.7.1 Methodology and methods

Of the nine research projects, five involved surveys (Study 5, 6, 7, 8, 9), with Study 7 describing itself as an audit, one used home visits (Study 4) and three a combination of home visits and surveys to collect data (Study 1, 2, 3). Study 2 used sampling techniques indicative of a RCT and randomly allocated participants to intervention or control groups as the basis of their research; they do not however define their project as a RCT. Whereas, Study 6 described the use of a "population based survey" (p216) to identify the level of locomotor function before then testing its hypothesis via a RCT. Study 4 reported their participants were approached through third parties, these were the Parkinson's Disease Society and a neurological sciences department. Whereas Study 5 contacted local child development centres and other services to identity children who met their inclusion criteria. Study 1, 2, 3, 7 and 9 reported contacting all patients who were discharged from a ward and or received joint replacement surgery respectively. Study 8 approached all prospective participants via a list provided by the assessing occupational therapist's service.

The earliest set of data was collected by Study 1 during 1975 and 1976 from participants with a range of diagnoses. The participants in Study 9 received surgery for joint replacements between January and June of 2014. Those in Study 2 were discharged from hospital in 1978 whereas the participants in Study 7, who had undergone a THR, received their surgery between July and November 1995. Data collection for Study 5 took place during April to December of 1986. The data collection points are not provided for Studies 3, 4, 6 and 8.

Though not specifically described as such by the authors, Studies 1, 7 and 8 were retrospective in nature, with the remainder being prospective. According to Law et al's (1998) guidelines, barring Study 2 and 6, the prospective projects appeared to fall either within the 'single case design' or 'before and after' design methods. However, given the limited methodological information provided and the age of most of the papers, it was not possible to definitively establish this.

Study 8 referred to the use of the Statistical Package for Social Sciences (SPSS V10) following data coding in relation to descriptive statistics. Similarly, Study 9 used the SPSS Predictive Analytics Software to analyse their data. Most papers presented their data descriptively rather than inferentially, the difference being the former is interested in the direct application of the data on a specifically chosen or selected population. Whereas the latter, inferential statistics, uses specific statistical tests to then apply the data to a wider/whole population.

The presentation of the data provided in several of the studies was unclear or inconsistent. For example, having indicated 73% of grab rails were in use, Study 1a did not state how many rails were on site. Similarly, Paper 1a referred to 32 of 41 commodes in use, however they also referred to chemical toilets but did not explain if these were included in the number of commodes provided. Although, the authors acknowledged the need to further modify the chemical toilets to enable their use, the clear difference in design between these and the commodes may have benefitted from a clearer separation of the results. As the report progressed, less detail was provided regarding the number of items provided and or in use. For example, as it is unknown how many items of toilet equipment were provided overall or by type, it is not possible to determine how many items remained in use which then affects the readers understanding of the results. Study 1a initially referred to 67% but then later 67 items of bathing equipment being in use. Similarly, discrepancies in the data were noted between Study 2a and 2b which respectively reported 80% and 82% of the control group participants were able to bathe. Additionally, the data presented in Study 1, for example paper 1a, reported 6% of the participants they surveyed bathed on occasion, whereas paper 1b stated this number as 8%. Similarly, paper 1a stated 79% of the 85 over tap rails provided were in use, whereas paper 2b reported 70% of the 85 were. In Study 3, 131 participants returned a questionnaire at the three month stage whereas the number returned at the nine month stage is not given. The impact of this on the results is not discussed by the authors of the paper.

The structure and content of the questionnaires in the nine studies were described in varying detail. Study 6 indicated the use of a population survey although the paper did not indicate in detail how this was developed.

None of the studies provided information relating to their philosophical or theoretical perspectives and assumptions. Despite this, whether directly or indirectly, all the studies indicated a perceived desire to explore the use of ADL equipment from the

participant's viewpoint following its practical application and use. This was predominantly achieved through the completion of questionnaires and surveys. Little information, if any, was provided around the development and application of the questionnaires; the exception being Study 8. Similarly, little or no information was offered in relation to the choice and employment of the data analysis techniques adopted.

## 2.7.2 *Methodological quality*

As reflected in Section 2.7.1, a high proportion of the 13 papers critically reviewed were found to provide little, if any, information related to the methodology and methods selected by the researchers. For example, details such as a description of the research design (Study 1, 2, 4), ethical considerations (Study 1, 2, 3, 4, 7), data analysis techniques (Study 1, 3, 4) and bias (Study 1, 2, 4, 7) were limited or omitted in their entirety. Where more than one paper represented a single study, the level of detail varied across them. As such, care was taken to compare the information provided. Evidence of this is provided below. The volume of information provided by Study 6 compared to that of Study 2 was marked, with the first study providing a higher level of depth and detail than the latter. The importance of document appraisal was highlighted here as a superficial reading as part of the screening process of Study 6 did not indicate a number of the arising anomalies. As such, inexperience or a lack of attention to detail may have resulted in the findings of Study 2 being dismissed in favour of those reported in Study 6. However, the rigour of each paper could be guestioned, in Study 2 due to the absence of information in general and in Study 6 as a result of poor rationale and a decision trail. Study 2 and Study 6 were both described as RCTs.

Table 2.13 depicts the level of information provided in the papers relating specifically to research ethics with the presence of a tick indicating the inclusion of that item. The shaded and non-shaded lines denote the nine studies. There is some evidence of the level of information or recognition of ethical issues increasing post 2000. This may be reflective of the changing landscape overtime, where perhaps the expectation of including this type of material shifts in line with the emphasis on evidence-based practice. Equally, journal expectations may differ with the reporting of outcomes considered more valuable, particularly as approved robust research protocols and ethical practice is an expectation with current research. Crowe and Sheppard (2011) who discussed this topic suggested the onus is on the writer of the paper to ensure accurate and appropriate information is included in the published article.

# Table 2.13: Data extraction – ethics

Study	Ethical Approval	Information	Consent	Inclusion criteria	Bias	Excluded/ Drop outs	GRADE
1a			✓ *		$\checkmark$		D2
1b			✓		$\checkmark$		D2
2a							D2
2b							D2
2c							D2
3				~		✓	D2
4a			✓			$\checkmark$	D2
4b							D2
5				~		$\checkmark$	D2
6	✓	✓ *		✓	$\checkmark$	$\checkmark$	B2
7		$\checkmark$		$\checkmark$		$\checkmark$	C2
8	✓	$\checkmark$	✓	~	$\checkmark$	✓	B2
9**	$\checkmark$						B2

\*Implied \*\*Identified itself as a service evaluation so ethical approval not required

Regarding the design of the research, Paper 1a indicated the use of a survey to collect data, no other information is offered in relation to the data collection method. In contrast Paper 1b, referred to section 2 of the survey which involved an occupational therapist visiting patients' homes to provide instruction on the use of equipment. Paper 1b further referred to participants having been interviewed, it is not made clear whether all 150 who took part were visited at home, contacted by telephone or post.

The presentation of data in several of the nine studies complicated the opportunity to make direct comparisons between their results. For example, the equipment related data in Study 3 is grouped into equipment types (walking, bathing, toilet, and dressing) whereas Study 1a itemises the equipment included in their research (i.e., bath boards, bath seats, mats, and rails). Whilst it is possible to calculate the itemised equipment into types to provide a broader picture, this is not the case when attempting to review more specific equipment items such as bath boards. As such, where equipment is grouped into types only, ascertaining which item or items may have benefited or affected occupational performance is limited. Where the type of equipment is unknown, for example in Study 4 where reference is made to 'bath rails', it is impossible to fully understand the link between the potential non-use of equipment with the mechanism of entering or leaving the bath. This is important when identifying equipment suitable for individual need.

Similarly, the presentation of data altered within the papers between raw data and percentages. For example, Study 1a referred to 56% of 72 bath seats being in use and 79% of 85 bath rails remaining in use. Often due to the lack of detail provided within the papers, attempts to convert percentages back to raw data and the reverse was challenging. As such, the opportunity to compare results across the studies was limited.

In addition, when reviewing the data analysis processes adopted combined with the presentation and cross referencing of the data within the 13 papers, discrepancies were noted. Examples include Study 1a, where the authors reported the provision of 325 aids within the section titled 'Bath Aids'. Before this they referred to 115 bathmats of which an undisclosed number were privately purchased, whereas in other sections, particularly those relating to toilet equipment though the percentage of items in use is given the number of items provided is not. These discrepancies challenge the reliability of the research.

Several anomalies were noted in Study 6. For example, initially the participants were defined by their geographic position [electoral wards] within the borough rather than by factors such as their age, diagnosis or gender. Later there was reference to the participants being 'well matched' in terms of gender and age; no further information is provided. Individuals within 14 of the possible 21 electoral wards were allocated to either the control or intervention groups. Within the abstract, the number of combined participants in the control and intervention groups was given as 79. However, when exploring the data this number did not correspond to the 545 participants who were assessed, nor with the 428 participants with no difficulties and the 415 with no disabilities they referred to. For the remainder of the paper, the number of participants corresponded to the activity of daily living under assessment. As such the data reported on changes in the activity rather than the individuals completing that activity.

## 2.7.3 Sampling and the participants

Except for Study 5, all the projects collected data from adult participants who had received ADL equipment following an assessment by an occupational therapist. Overall, the known participant ages ranged between 49 and 82 (Study 4), their 50s and 90s (Study 7) and 27 and 93 in Study 8. Study 3 indicated their participants were aged over 40 years with average ages of 65, and Study 5, between age four and 12. Six of the studies with adult participants indicated the majority were either aged over or averaged ages within their 60s (Study 1a, 2, 3 and 4). The participants in Study 6 were all aged 85 years and above, whereas Study 8 described their participants mean age as 71.3 years. Study 9 provided no age-related data though given the nature of the surgical interventions the participants could be assumed to be adult rather than paediatric.

The number of participants also varied; Study 5 collected data directly from 28 participants. The remaining projects sourced data in ascending order from: 55 (Study 8), 63 participants (Study 7), 81 participants (Study 4), 100 participants (Study 2), 114 (Study 9), and 150 participants (Study 1). Study 3 also reported a total of 150 participants, however as five of these had both hips replaced during the study they were counted twice as such there were 145 individual participants. Study 8 reported an overall response rate of 40%. Whilst this is considered an acceptable survey response rate, the authors of Study 8 did not discuss whether a higher number of respondents would have affected their overall findings and conclusions. Initially, the largest number of participants was reported in Study 6. However, after visiting the 545 potential participants, a total of 79 were allocated to either the control or intervention groups.

Patient diagnoses was generally not dissimilar across the nine studies. Six of the nine studies indicated the presence of arthritis and given the ages of the participants in two of the studies (Study 4 and 6), arthritis was likely to be present. Other diagnoses included those with a neurological origin (Study 1, 2, 4, 5 and 8), or were respiratory or cardiovascular in nature. Study 5 which involved children reported diagnoses of cerebral palsy, brain damage, spinal muscular atrophy, and other complex needs.

Study 4 acknowledged the potential for bias toward a greater level of disability within their participant group. They reported how several individuals approached did not consent to an occupational therapy visit to review their needs. As it is not indicated whether the role of the visiting occupational therapist was given, it is unclear whether this influenced the uptake of participants. Similarly, the proportion of elective or trauma surgeries was not given in Study 7. They state 'all' patients who received a THR were forwarded a copy of the questionnaire. Study 6 acknowledged the overall level of functional ability within a population may have been affected if the number of participants who participated in their research was higher. They suggested the functional level of the nonparticipants may have been higher than those who participated.

## 2.7.4 Equipment provided and reviewed

As demonstrated in Tables 2.5 through to and including Table 2.13 the range of equipment explored was dominated by bathing and toileting items, the exception being Study 8 which focused on stairlifts.

Two projects explored a range of equipment associated with bathing and toileting (Study 1 and 2). Study 4, predominantly reported on bathing, feeding, and toileting equipment, though similarly to Study 1, also included other miscellaneous items. Surprisingly, given the importance of hip precautions, Study 4 did not include furniture raisers as part of their research into total hip replacements, rather they excluded these from the findings and the report. The use of equipment provided as part of a hip pack, following THR surgery, was also explored by Study 3 and Study 7. They referred to: walking, bathing, toileting and dressing or RTS, easi-reachers and LHSHs respectively. Study 9 which explored joint replacement surgery included dressing, some toileting and equipment raisers. Whereas Study 5 investigated paediatric bathing equipment and Study 8 stairlifts. The focus of equipment in Study 6 involved RTS, teapot tippers, tap turners, LHSHs and double handed saucepans. Whilst contact between the researcher and occupational therapists in Study 5 identified equipment in use in clinical practice,

there was no acknowledgement as to whether the equipment selected for the trial and found to be effective would be available within the differing local authorities as statutory provisions. The impact of criteria and funding was not alluded to.

#### 2.7.5 Thematic coding and analysis

As identified in Section 2.1, this review was not intended as a systematic review of the literature. While it followed a number of the principles of a systematic review, it did not adhere to the strict protocols as identified by Ridley (2012) and Higgins et al (2019). In line with this, there was no attempt to complete a meta-analysis or meta-synthesis which is an expected element of a systematic review (Higgins et al 2019). Except for Hart et al's (1990) RCT, the remaining 12 papers included within this literature review appeared neutral in terms of their approach to research. For example, there was no reference to paradigms, philosophical or epistemological stance or a chosen methodology. As the findings of the papers were reported descriptively using a narrative format, the decision to follow a thematic analysis process was made. The use of existing research as a secondary source of data was considered appropriate to this type of analysis (Braun and Clarke 2013). In addition, this process appeared to be the most appropriate as it facilitated the organisation and synthesis of important and relevant data around a given topic (Braun and Clarke 2006, Booth et al 2016). Two papers which appeared to use a similar approach were sourced, these were Sinclair et al (2006) and Broadhurst and Harrington (2016). The analysis of this review involved identifying information of analytic interest before adopting an inductive approach to developing the themes. Exploring the themes and associated issues at a latent level was also completed. The process of thematic analysis outlined by Braun and Clarke (2006; 2013), Clarke and Braun (2013) and Clarke et al (2015a) were used a guide. All 13 papers were explored systematically to identify relevant characteristics/codes, this was repeated several times. Similar characteristics/codes were grouped together to form sub-themes; these were then developed to create the themes. Table 2.14, summarises the characteristics/codes, sub-themes and themes. The themes arising in Section 2.7.5 are reported and explored in greater detail in Section 2.8. The themes are: utility, the patient's voice, improving services and outcomes and quality of life. Due to the confines of the data content, the volume of characteristics/codes, sub-themes and themes are limited.

# Table 2.14: Summary of themes

Characteristics/codes	Study	Sub-themes	Themes
Usefulness/useful	4, 5, 7, 8	Use	Utility
Helpful/valuable/ practical/benefits/	1, 4, 5, 6, 7, 8	Usefulness	
essential/satisfaction		Efficacy	
Number issued In use/not in use	2, 3, 6 1, 2, 3, 5, 9	Practicality	
Length of time in use	5, 7, 8, 9	Benefits	
Design	1, 2, 5, 8		
Environment	1, 5, 8		
Quality of design	1, 2, 5, 8		
Acceptance	1, 5		Patient's voice
Private purchasing	1, 7		
Positive perceptions of equipment	5, 7, 8, 9		
User's voice	3, 5, 7, 8, 9		
Timely provision	1, 2, 3, 7, 8, 9	Procedures/ processes	Improving services and
Underprovided	2, 4	Quality of assessment	outcomes
Lack of review/ follow- up/recovery	3, 4, 8, 9	Further research	
Outcomes	8		
Training/instruction	2, 9		
Self-care/bathing	1, 2, 3, 4, 5	Independence	Quality of life
Toileting	1, 2, 3, 4, 6, 7, 9	Dependence	
Mobility/transfers	2, 3, 4, 9	Impact on ADLs	
Dressing	3, 4, 6, 7, 9		
Feeding	4		
Others/non-specific	3, 6, 8, 9		

#### 2.8 Discussion

The themes developed from the thematic analysis process outlined in Section 2.7.5 are used as the structure for discussing the findings of this literature review. The four themes are, Utility, Failing to Give Voice, Improving Services and Outcomes, and Quality of Life. The following sections include a discussion of the direct observations taken from the nine research studies included whilst also highlighting any perceived omissions that in hindsight may have affected or enhanced the outcome of the research. Other issues such as limitations, implications to occupational therapy practice and future research are also discussed. Then follows a section on the limitations of this literature review before conclusions and recommendations are offered.

#### 2.8.1 Utility

Within the context of this literature review and the research project, 'utility' is used as an umbrella term to encompass elements such as: the use, usefulness, efficacy, practicality and the benefits, if any, equipment for activities of daily living provides. The term 'use' refers to the application of equipment for its intended purpose, 'usefulness' indicates the advantages or disadvantages of the equipment in relation to its purpose whilst 'efficacy' highlights if the intended outcome is achieved. 'Practicality' is an indicator of how easy equipment is to use and the 'benefits' refers to the impact or difference the item or items make. Either indirectly or directly, all nine studies referenced the utility of the equipment researched. This first theme (2.8.1) is further divided into three sub-themes. These focus on issues surrounding the types of equipment provided and the length of time they are in use (2.8.1.1), the compatibility of equipment with the environment (2.8.1.2), and the usefulness of the equipment (2.8.1.3).

#### 2.8.1.1 Equipment in and not in use

This concept commonly manifested on the particular focus of issues related to the number of equipment items provided (Study 1, 2 and 3) and or whether these remained in use over time (Study 1, 2, 3, 5, 9), and for some more specifically over what period (Study 5, 7, 8, 9). For example, whilst Section 2.7.2 highlighted issues with the reporting of data in Study 1, (particularly paper 1a) it found 68% or 220 of the 325 items of bathing equipment issued remained in use at the time the survey was conducted (between six- and 24-months post hospital discharge). However, there was a lack of

clarity surrounding the range of time over which the equipment was supplied, and the survey conducted.

Though it was reported in Study 1 that the patients were discharged from hospital during 1975 and 1976 there is no additional data indicating the average or precise time frame between discharge and individual participants completing the questionnaire. If this information were available, it would help establish whether certain items of equipment remained in use for a longer time period than others. Additionally, though some detail was offered in respect to why equipment was not in use, this was neither explored nor commented on in relation as to whether the researchers considered this number acceptable. Neither did they indicate the need for further research in this area. However, as Study 1 was published prior to the other eight, and given the outcome of this review which found little published research on the topic of ADL equipment, at the time the ability to compare their findings with others would have been challenging. In a follow-up, Study 2 found the overall use of bathing equipment had increased to 80% from 68% in Study 1. The participants in Study 1 were visited between six and 24 months to enquire about the long-term use of equipment. Whereas participants in Study 2 were contacted three to six months later. Had the survey in Study 2 been completed within the same timeframe as Study 1, the results may have been less encouraging and mirrored those of Study 1.

Study 3 highlighted the number of equipment items participants had access to and were in use at the point of admission for a THR; then at three and nine months postsurgery. Their findings indicated the amount of equipment increased post-surgery and then decreased at nine months. The Study accepted the volume of equipment prescribed/issued at the three month and nine month stages was not uncharacteristic given the nature of the surgery. Whilst they acknowledged participants may have been less affected by their arthritis prior to timely surgery compared to other facilities they stopped short at suggesting the volume of equipment provided and in use may correlate between the two. There was a clear difference reported between the number of items in the participant's possession and those in use at each stage of the data collection points, this was particularly evident with the dressing equipment. The reasons offered for this anomaly included poor assessment of need, equipment selection and instruction which could have been linked by the authors to the high number of dressing aids provided, and items not being returned. The authors suggested, had they gathered information to establish how long the equipment was in use for post-surgery they could have addressed this issue. However, it is unlikely this

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specific data alone would have achieved this without also enquiring why the participants had ceased to use it. For example, had they recovered sufficiently to no longer require equipment or were they unable to use it and if so, why. Further ambiguity was later raised when the authors stated a high volume (more than half) of the items of equipment were returned by request between the mid and final data collection points. Clarity surrounding the use of the phrases 'in-use' and 'used' by the authors may therefore have been helpful.

A key objective of Study 7 explored whether equipment was issued consistently by occupational therapists to individuals following a THR in line with locally developed standards. Whilst the audit captured information relating to the number of items issued to some participants it did not explore non-provision to others. For example, it did not account for individual need such as the recommended height for transfers where the person was taller or shorter and thereby may or may not have required a RTS. The alternative they offered referred to the level of informal support the individual received at home. Whilst this is unlikely to have affected the use and non-use of equipment it does compromise the findings of the objective overall as equipment was clearly not issued to all the participants. Overall, the study highlighted the usefulness of equipment to most of its users which resulted in a Trust led equipment service for THR patients which compensated against the withdrawal of social services funding.

In its conclusion, Study 7 implied a known link between the withdrawal of social services funding and non-compliance with hip pack standards. In the introduction the purpose of the audit was reported to have been developed because of the withdrawal of funding and a need to understand the clinical implications of this and equipment compliance in terms of whether equipment was required. As such, the driver of the audit and the conclusions did not meet. The report neither indicated whether the standards for equipment provision post THR were amended as a result of the research. Additionally, Study 7 raised the issue of equipment remaining in use past the recommended time frame. Due to the design of the questionnaire the opportunity to explore this in greater detail at the time was not possible and no explanations are provided by the authors.

As may be expected, Study 9 found participants who received the more invasive form of surgery (PTHR) continued to use equipment for longer than those with the less invasive type. Equally, they acknowledged some participants may have reported this to appear compliant and how the possibility of comorbidities may also have hampered recovery in this participant group.

#### 2.8.1.2 Design and the environment

Several studies, including Study 1, 2 and 5, raised issue with the incompatibility of equipment design with bathroom furniture, such as baths, which they found contributed greatly to equipment non-use. Equally, the environment affected participant's opportunity to use equipment due to the design of properties (Study 1 and 2). Despite being available to the UK market, the consistent incompatibility of equipment manufactured internationally was highlighted by Study 5; they referred specifically to bathing equipment.

Study 1 highlighted that difficulty with negotiating the stairs prevented access to essential facilities such as bathrooms located on the first floor; they found this affected more than 40% of their participants who lived alone. Additionally, bathrooms were described as compact which negated the use of some items of equipment and access for those with walking equipment. Access within separate toilets was also challenging as was environments with doors hung to open inward. The research, conducted in Leeds, raised the issue of poor access and equipment provision with the design of post war and existing housing stock affecting individuals for some time to come. It is important to note that more than 40 years later, in many towns and cities the same housing stock remains and so continues to be a barrier for many individuals who would benefit from equipment. In contrast however, few houses now function with an outdoor toilet only. In Study 2, a follow-up of Study 1, the authors reported an increase in participants' accessibility to essential facilities. They did not elaborate further. For example, had there been a change in housing stock or was there a difference in the level of function affecting the ability of participants to access facilities. This is particularly pertinent as they advised how facilities were across more than one level which implied a greater need to be able to negotiate steps and stairs. Furthermore, in comparison to Study 1, Paper 2c stated access to the bath was not affected by the size of the bathroom.

In Study 2, 31% of the bathing equipment was found to be inappropriate for the type of bath in place. For example, the insufficient length of the adjustable brackets prevented secure fitment to the bath sides whilst the bath seats (the metal hanging style of the Rentwood and Farnham seats) were incompatible with acrylic baths. Also, several bathmats did not adequately secure to the bottom of the bath. Study 2 linked the poor

design of equipment with satisfaction levels. Flaws in the design of free-standing toilet equipment was raised in Study 1, they suggested the opportunity to screw items to the floor would greatly improve stability and increase use. The opportunity to select frames with flanges to enable secure fixing to the floor were available in the 1990s; possibly before. The link between equipment design and the safety of the participants was raised by several of the studies.

Concerns with the height and comfort of bathing equipment was raised in Study 1. Paper 1b appeared to advocate the usefulness of this equipment suggesting the needs and abilities of the users determines the height required; they cited height and muscle power as primary factors. However, they then stated how the weight of the equipment affected users with arthritis, they did not however highlight the importance of joint protection for those with rheumatoid arthritis. The overall height of equipment was raised by Study 5, who commented on the volume of water required to cover the participant. Presumably, at the time the research was conducted water was heated through a regular electrically powered boiler which stored water in an immersion tank. The cost of heating the water and the tank size would determine the volume of water available. Anecdotally, the height of equipment in relation to the depth of the bath remains an issue today. This is compounded by an increased awareness of the impact of water consumption on the environment coupled with the use of water and power meters. A further challenge raised by Study 5 included the storage of any equipment when not in-use. Furthermore, where equipment was advertised as dual-purpose, i.e. for use in more than one environment, the overall results were disappointing as drying equipment in between use was found to be impracticable.

Whilst Study 1 suggested informal support from others may have alleviated some of the impact of environmental and equipment design, they recognised this may be unreliable due to other commitments or the age of the person assisting. Despite raising the issue of informal support, researchers in Study 6 were unable to compare the difference equipment provision had made to their participants in this area. Neither did they examine the difference the provision of equipment alone had made. Rehousing was a further consideration. In current times, the lack of good quality social housing is well reported and changes in lifestyle due to greater opportunities often results in families living at greater distances than previous. The age of informal carers remains an issue whereas for others the opportunity to be supported by statutory services for social bathing is no longer an option due to changes in national and local policy.

Interestingly, Study 1 recommended cork as the ideal surface property of bath boards and criticises plastic as "cold and slippery" (1b, p205). In contrast, unlike bath boards of old, modern bath boards provided by statutory services are more likely to be fabricated in plastic (Polyvinyl Chloride) due to their durability and ability to meet strict infection control measures. Paper 2b, published in 1981, recognised the use of cork in the design of bath boards as an inferior material.

#### 2.8.1.3 Usefulness

Study 1 discussed how the design of bath seats, due to their height, affected participant use, they specifically referenced the inability of individuals to be submerged when bathing. Along with issues of comfort, they also raised concerns with the quality of the secure fitment of bath seats; stating they tended to slip. However, whilst the quality of the suction cups can affect fitment, with experience the secure fitment of seats is affected by the cleanliness of the bath surface and the type of bathing products used by the individual. This was not raised by the authors of Study 1. Whilst a high number of bathmats were found to be in use, indicating their usefulness, others were not due to issues with a lack of suction and the rubber degrading over time. With experience, whilst bathmats continued to be supplied through statutory services during the 1990s, recipients were advised to be aware of the rubber deteriorating and as such the need for regular replacement. Study 1 did not indicate whether participants were advised of this, so it is unclear whether this was known at the point of provision.

Regarding over tap rails, these were found to be useful when facilitating a step over the bath side or raising from a bath seat rather than when attempting to rise from the bath bottom (Study 1). A potential correlation between the low numbers of participants using the bath board to negotiate the bath sides and the higher number of over tap rails in use was not made in Study 1. While Study 1 does not state how many participants used the over tap rails to facilitate stepping over the bath sides, Study 2 (paper 2c) found that with increased instruction the number of over tap rails was reduced. However, paper 2c later reported how participants found the design of the over tap rails limiting as they prevented access to the space available at the tap end of the bath when washing lower limbs, particularly the feet. Personal recollection of this equipment, however, recalls how the rail could be lifted up and down above the taps to allow access to this end of the bath and to not impede access for those who did not require its use. It is possible earlier versions of the over tap rail were fixed. When referring to usefulness, Study 4 simply stated how most of their participants found the equipment useful. The item participants found least useful were 'egg cups'. A high proportion of

the respondents in Study 6 (93%) indicated they would have considered privately purchasing an item of equipment. Only a small number of the respondents in Study 6 reported finding the equipment not useful. Raised toilet seats were the most useful followed by helping hands. Whilst the authors of Study 6 acknowledged participants may have been less inclined to purchase equipment had they not had the opportunity to use them first, they do not indicate whether the cost of items was disclosed to the participants. This knowledge may have affected their responses to this question, particularly if more than one item was required.

Generally, Study 4, correlated the overall usefulness of equipment with its practical application. The authors of Paper 4a further suggested equipment design and utility, along with ease of sourcing were important factors when considering usefulness.

Whilst Study 6 did not explicitly state their intention to explore usefulness, their results indicated that those issued with a teapot tipper, tap turners and a double handed saucepan experienced greater functional ability post provision (four weeks later). With regard to the RTS and shoehorns, two participants experienced an increase in function whereas only five out of 10 of those issued with a shoehorn observed any improvement. Study 6 concluded that early screening is cost effective with the potential to reduce the effects of disability on function, particularly where there was an identified need. They also raised the design of equipment, diagnosis and the willingness to accept equipment influences the effectiveness of equipment use.

A key issue raised by Study 1, and which remains relevant today, is who is responsible for emptying the contents of a commode in someone's home. Whilst the collection and removal of the content of commodes can now be alleviated by special commode liners the task still requires someone with the physical and cognitive ability and dexterity to remove and replace them safely and hygienically.

## 2.8.2 Failing to give voice

The following theme emphasises how the available literature disappointed in evidencing the benefits of equipment provision. Equally, it demonstrated how the positive and negative elements of ADL equipment were often approached somewhat superficially by the researchers.

#### 2.8.2.1 Lack of evidence

Several of the papers highlighted the lack of research available. For example, having recognised the importance of equipment in maintaining and promoting dignity and independence, Study 1 identified the lack of research surrounding the use of equipment, particularly from the perspective of those who used it. Similarly, Study 5 found little professional guidelines, assessments or published research involving paediatric bathing equipment. Though without a direct emphasis on equipment, Study 4 referred to the lack evidence pertaining to occupational therapy practice and Parkinson's. Study 8 found a paucity of occupational therapy and equipment focussed literature relating to the UK Enhanced Recovery after Surgery pathway.

Within its recommendations section, Study 3 raised the need for further research relating to equipment use, particularly to explore why equipment is prescribed, in or not in-use and the types involved. The authors of Study 7 expressed an interest in researching whether the 'usage' of equipment was affected by those who resided with a caregiver or alone. Study 7 and Study 9 raised the issue of a lack of supporting evidence surrounding equipment use following a THR and TK/HR respectively, both studies recommended the need for additional research in their respective areas. Furthermore, Study 8 highlighted how research findings, theirs, provided evidence to those who purchased equipment and commissioned services.

## 2.8.2.2 User knows best

Study 1 concluded that where users of grab rails had been consulted in identifying the required position, a high usage rate was found. How this was determined in comparison to those who were not, was not reported. Study 5 stressed that provision of equipment was based on ability and function and not condition led. Though not stated implicitly, this statement acknowledged that differences in presentation affected how well a child was able to use the equipment under trial.

## 2.8.3 Improving services and outcomes

Theme 2.8.3 assimilates the factors which affected the clinical practice of the occupational therapists who participated in the research included in this literature review. The sub-themes are training and instruction, timely provision, review and follow-up, and returns.

#### 2.8.3.1 Training and instruction

Study 1 highlighted how a lack of instruction may have resulted in a low number of participants using bath boards when negotiating the bath sides. Paper 1a asserted the importance of instructing equipment users to sit rather than stand when transferring over or negotiating the bath sides. It could have been argued that a risk assessment of an individual's ability to step over the side versus the use of the bath board to facilitate transfers would have determined the most appropriate and safe option for that individual. Alternatively, Paper 1b advised of the recruitment of an occupational therapist to provide instruction on the use of equipment, including bath boards. However, as the number of participants visited was not disclosed it is unknown how many participants received additional instruction, how many adapted the method of negotiating the bath sides to suit their needs or if recall was affected by issues of poor memory. Paper 1b disclosed an increase in the number of bath boards in-situ (to 81%) and in use (95%) in what they refer to as the 'treated group'. There is no explanation of the anomaly between paper 1a and paper 1b.

Study 2, a follow-up of Study 1, also utilised an occupational therapist to visit participant's home environments to offer additional instruction and a 'wet trial' of the bathing equipment to those in the treatment group. Unlike Study 1, the authors of this second study acknowledged a high number of their participants could not recall having had received instruction prior to their discharge from hospital. While all the participants in the treatment group were visited there is a broad timeframe across which these visits took place. For example, in paper 2c a table indicated that two participants were visited (either twice or three times) within a one week period whereas at the opposite end of the spectrum, two participants were visited within a seven week timeframe. The rationale for this is not alluded to in the report and as such the effects of this were not addressed, particularly in terms of some participants having had the opportunity to practice with their equipment over others which may in turn have affected dependency levels.

The provision of additional equipment once participants were discharged from hospital was raised by Study 2. It found 27% more of the treated group received additional bathing equipment once at home. They described this as an underestimation of need by the inpatient occupational therapists but did not explore this in greater detail. Explanations may have included the difference in the design of the bathing environment in the hospital to that at home or a change in ability between the inpatient

assessment and returning home. A further explanation may be representative of the equipment being incompatible with the type of bath in place; this point is raised by Study 2 (Section 2.8.1.2). Similarly, Study 4 proposed their participants, regardless of a previous visit by occupational therapists (one third), had simply not had their ADL equipment needs met. Though not stated, this comment implied a less thorough or a lack of understanding of Parkinson's disease on functional activity and performance. Additional bathing, toileting and feeding equipment was provided by the research occupational therapist in Study 4 which suggested an overall deficit in all functional domains during any previous assessments. As Study 2 has not indicated which additional items were issued it is only possible to speculate whether, as with Study 4, there was a general gap in knowledge. As with Study 2, Study 4 did not indicate the time difference between the original assessment and that of the research occupational therapist. Neither did they recognise the possibility that participants may have deteriorated over time thereby requiring the additional items they referred to. Whilst this type of omission could be seen to undermine findings, on this occasion it advocates the need for frequent follow-up visits as it highlighted the unseen and unreported deterioration of functional need. Whereas conversely, it may also indicate over prescription by those with a specialist interest in older people or Parkinson's disease.

Question one of the questionnaire used in Study 9 asked participants whether the occupational therapists provided information and or advice which was useful either as part of a 'joint school' or following the surgical intervention. Of the 114 (58%) respondents, 97% of those who received a PTHR or an ATHR and 100% a TKR indicated the information they received was useful. A three-point Likert scale was used to capture this and the data for question two and three. The options available were 'yes', 'no' and extremely'. As with the other eight projects the opportunity to explore topics in greater depth and detail were missed. For example, question 2 asked whether the equipment remained in use whereas question 3 enquired about the impact of the equipment on ADLs. The final question used a five-point scale to explore if the equipment facilitated a more timely discharge; the additional options were 'partly' and 'not'. As with all of the studies included, the opportunity to gather the patients' voice was missed.

#### 2.8.3.2 Timely provision

Study 1 indicated the participants they surveyed received equipment within days or months post-discharge. Prior to this they stated how a delay in equipment provision affected the maintenance and improvement of functional levels of individuals

discharged from hospital. What is not clear is whether the participants reported an effect on their dependence or independence or if the authors had concluded this based on the waiting times provided by the participants. Similarly Study 2 found disparity with equipment delivery times, with 39% (control group) and 74% (treatment group) receiving prescribed items within two weeks. A small number of each group (17 and 6 respectively) waited for longer than three months. The discrepancy in time between the control and treatment groups was not recognised and therefore an explanation not provided. The authors of Paper 2c expressed their disappointment at the lack of improvement in the delivery of equipment based on the findings of Study 1. While Study 1 raised the issue of untimely provision of equipment the report does not indicate, other than within the publication itself, how the information was otherwise disseminated or intended to inform or influence stakeholders.

In contrast, after revisiting all of the participants four weeks after provision of equipment to those in the intervention group, a number of those in the control group of Study 6 were found to have improved. Unfortunately, if the reason for this was explored it is not given in the report. For example, had the participants improved functionally after recovering from a short-term illness and or was the task now completed by another.

#### 2.8.3.3 Review and follow-up

The high number of un-used and unreturned equipment items was attributed to the lack of a system of review or follow-up post provision by Study 1. They stated the occupational therapists' role was "concerned with fitting aids or assessing for rails" (1a, p245). Given this statement it could be argued as to whether, similarly to today, the focus of equipment provision was one of timely hospital discharge rather than necessarily its quality. Some confusion arose with the procedure described in paper 2c. It referred to a request for participants to demonstrate their technique of accessing the bath in the absence of equipment and support from others. This was directly following a comment made by the authors who stated equipment related instructions were given prior to a demonstration by the participants. Further discrepancy arose in relation to the third visit. Papers 1a and 1b both indicated the third visit was conducted if there were ongoing concerns around the participants understanding of the equipment and how to use it safely. Whereas paper 2c stated a delay in equipment provision resulted in the need for this third visit. The inconsistency of the procedures reported contests the replicability and dependability of the findings. Study 3 suggested inappropriate provision and poor instruction as a rationale for the non-use of equipment and a simple failure to return items not in use. Whilst they recognised the benefits of a ward-based

loan service they also recognised the challenges involved. For example, the lack of opportunity to follow-up provision and the logistics of replenishing stock. Both Study 2 and Study 3 raised the issue of visiting properties. Whereas Study 2 highlighted the benefits of some form of follow-up visit post discharge, particularly to ensure the correct use of equipment and to resolve any unforeseen minor issues. Study 3 considered visiting the home environment to loan equipment as an unrealistic and impractical option geographically and or when it was then found to be required on a longer term or permanent basis.

## 2.8.3.4 Returns

Linked to review and follow-up, Study 1 acknowledged a significant number of equipment items were unreturned despite not being in-use at the time of their survey. Study 1 referred to items "not reported" (1a, p245), the intent of this statement was not clear. It could suggest that the providing service was informed of the non-use of equipment but then failed to collect it, that equipment provided was not adequately recorded or that participants simply failed to inform the appropriate service of the need for collection. The authors also suggested that some participants chose to store the item/s for future use, should it be required. As discussed in Section 2.8.1.1, though ambiguous at times, Study 3 highlighted the poor return of equipment found to be not in-use. The disparity between services (at the time) is also highlighted. Whilst having recognised that certain equipment items may have remained in-use for longer periods of time, Study 3 then indicated that some equipment types were supplied by more than one service. This, therefore, could have accounted for the high volume of equipment not in-use remaining on site as participants may have in fact attempted to return items to the incorrect service. This may have been indicative of a poor returns system rather than participants lack of initiative. Study 3 cited the benefits of "a joint system of storage and distribution of aids" (p400), an issue later addressed by the advent of the Integrated Community Equipment Stores (ICES) which enabled inpatient occupational therapists to access equipment classed as essential for discharge.

## 2.8.4 Quality of life

Study 1 referred to the impact of toileting equipment on their participants. They highlighted that 50% of toileting equipment in use promoted independent access and use of the toilet. In contrast however, when they referred to other toileting equipment such as urine bottles and bed pans the authors did not indicate whether these enabled independence or reliance on others. Due to the additional advice and instruction

offered by the visiting occupational therapist in Study 2, they found 36% of the treatment group were able to bath with half of the group doing so independently. When comparing levels of morale, Study 2 found a difference between the participants in their control and treatment groups. The participants who had received the standard service indicated a lower level than those in the enhanced group who reported having higher levels of morale linked to their sense of 'improvement'.

Study 4 reported a link between levels of dependency and the number of equipment items in the possession of participants. They also made a direct link between the value and usefulness of equipment, with reference to its practical use. It is unclear whether 'value' referred to the impact on quality of life or that which was born out of a necessity. In other words, it enabled the participants to do something out of need rather than want.

Having investigated the experiences of children bathing using a range of equipment through the identification of practical characteristics, Study 5 indirectly indicated how the quality of the activity could be improved. Though not referencing quality of life specifically, they acknowledged how bath time could be improved through the selection of equipment which enabled the child's full immersion in the bath water. Anything less resulted in bath times that were purely perfunctory rather than for leisure and play. As such, appropriately selected equipment, particularly that which provided postural support improved the care givers experience of assisting the child which in turn improved their and the child's experiences.

As with the other eight studies, although Study 6 did not explicitly refer to quality of life the authors did suggest that assessment of ADLs in all individuals over a certain age would increase independence and is more cost effective than completing occupational therapy assessments on a needs must basis. There appeared to be an assumption that once individuals reached a certain age their functional ability will have plateaued in line with their diagnosis and as such no additional assessment would be necessary. Anecdotally this is not the case, in the experience of the main researcher, conditions and function do not plateau. To prevent the need for further assessment, it would be necessary to provide equipment to meet all eventualities which feeds the argument of dependency versus independence.

Study 8 used a standardised questionnaire (The QUEST) and a purposefully developed secondary questionnaire to explore the impact of stairlifts on its users; this

included factors associated with quality of life. However, the paper contained little feedback other than to report, in percentages, how the stairlift affected where the user slept, washed and the need for rehousing. Similarly, in terms of independence, quality of life, health and the level of assistance required the benefits of a stairlift was presented in the form of a five-point Likert scale which was perfunctory rather than enlightening. Here, the use of closed rather than open questions resulted in the missed opportunity to gather rich in-depth data.

## 2.8.5 Limitations of the nine studies

Few of the studies defined the terminology they adopted, except for Study 1 which described 'toileting' as all of the component parts required to complete this activity. This included mobilising to and from the toilet, adjusting clothing and personal care. They do not however then elaborate as to whether the toileting equipment improved or impeded the act of personal care or what types of walking equipment was used by the participants. The lack of clarity around the use of terms 'used' and 'in-use' affected the readers ability to fully appreciate the volume of equipment actively in-use at a given time. The word 'used' could imply currently in-use or that it had been previously 'in-use' but was no longer.

Where two or more papers represented one study, the information presented in the individual papers did not always align. For example, where reported aims of the research matched the emphasis of the information provided in one paper then differed from one equipment type to another or reported differing factors associated with them. None of the papers acknowledged this.

Of the nine studies, Study 7 and Study 8 referred explicitly to the act of gathering information from the perspective of the equipment users. The focus of Study 7 involved the proposed method of equipment provision whereas, Study 8s interest lay with the equipment item itself. Despite having indicated space for free commentary, Study 8 provided a limited number of participant excerpts. Of these, only one reflected the impact the equipment had on the user and their family compared to the other seven comments which related to utility. Overall, Study 8 focussed on the utility of the data collection method/s rather than an in-depth exploration of the equipment's effect on the participants.

With the exception of Study 3 and Study 9, the seven other projects indicated an interest in factors such as 'value', satisfaction' and 'benefits'. However, these were

investigated on a superficial utilitarian 'yes/no' level rather than attempting to define or explore what this meant to the individual participants.

Overall, due to the similarity of the data collection methods adopted by the researchers the information collected and subsequently reported was objective rather than subjective in nature. Whilst it could be argued this type of data does reflect the participant's perspectives, it could be equally suggested this is limited and lacks an exploration of a deeper meaning and understanding of equipment and its use.

## 2.8.6 Implications to practice

Stowe (1979) the author of Study 2a and one of four in Studies 2b and 2c summed up their feelings in the following quote:

"All too often patients are discharged from hospital and dropped like a sack of coal and left, ignored" (Paper 2a, p169).

The nine studies raise several issues relevant to clinical practice both past and perhaps which remain relevant to the present. Firstly, the delay in timely provision, which according to the author of paper 2b was "unacceptable" (p41) is common in two of the studies (Study 1 and 2). The advent of joint community equipment stores which provide inpatient occupational therapists with improved access to equipment essential for discharge, now ensures equipment is available prior to or at the point of discharge. Equally however, changes in policy to reflect timely discharge from hospital and the definition of equipment essential for discharge, the delay in assessment for and provision of equipment for bathing may in fact be similar or greater than patients previously experienced.

The effectiveness of the place of assessment is also highlighted, particularly with the earlier studies. They found (Study 1 and 2) that additional equipment was required when the assessment had taken place in an artificial environment compared to that of the participant's home. The motive for this was unclear, for example was this due to poor recall of the environment, the desire to return home outweighing the perceived time required to complete assessments and receive equipment, or over prescription within the home environment due to a change in power as the service user felt more empowered to express their problems. The findings in Study 2, suggested that assessment and follow-up in the home environment reduced the volume of unused bathing equipment. However, caution should be applied here as the survey conducted

was completed within an earlier time frame compared to others such as Study 1. As such, Study 2 may not have captured the longer-term use and non-use of equipment. Whilst the opportunity to visit patients and service users multiple times would be welcomed by many occupational therapists and other professionals the reality of this due to the limitations of service remits and the lack of resources makes it unlikely. Whether this is achievable through robust outcomes and evidence is not known.

Thirdly, Study 2 found that where additional instruction was provided the number of unused items of equipment was reduced. They concluded the two were indicative of each other.

The studies highlighted a number of practical issues related to equipment non-use some of which may remain relevant to today's clinical practice. For example, poor design/fitment (Study 1), unacceptable waiting times (Study 2) and the lack of a review or follow-up process (Study 1 and Study 2).

## 2.9 Limitations of the Literature Review

There are several recognisable limitations to this review of the literature. Firstly, as reported in Section 2.5, despite the overall volume of literature related to equipment, including that for activities of daily living, the number of peer reviewed research papers found to be relevant and included in this critical review was limited. The lack of research evidence supporting clinical practice was historically highlighted by Ravetz (1987) and Chamberlain et al (2001).

Within the scope of the main research project, completing a systematic review as defined by Higgins et al (2019) was not feasible. However, consideration of the characteristics of a systematic review were adopted where possible. This included a clear research question, the inclusion of a methodology and a findings and discussion section.

Whilst the intention of this review was to explore research over time, the publication date of a high proportion of the papers are considered outdated in terms of clinically relevant evidence-based practice. Three papers were published in the 1970s, five in the 80s, two in the 90s and one each in the 2000s and 2010s. To further compound the lack of published literature, it was disappointing to discover four of the papers related to three already published studies. This resulted in a total number of nine research projects which met the inclusion criteria. As such, the opportunity to meaningfully

collate and compare the content and findings of the research sourced was less extensive than hoped. The paucity of published peer reviewed research highlights the poor volume of evidence relevant to occupational therapists' clinical practice and ADL equipment. Equally, the quality of the research examined was found to be fundamentally poor. These issues are of particularly importance and raise a few concerns given the synonymous relationship between occupational therapists and ADL equipment which, as outlined in Sections 1.2.1 and 1.8.6, is considered a core element of occupational therapy practice. Given that simple online searches related to the role of occupational therapists included reference to equipment or technology, the lack of research evidence related to this significant element of practice is concerning. As demonstrated in Chapter 1, there is a clear history of the use of equipment by occupational therapists which over time developed to include that for ADLs. Furthermore, the powerful physical and emotional relationship between service users, occupational therapy staff and equipment which is explored and examined in Chapters 4, 5 and 6 and further discussed in Chapter 7 highlights the importance of knowing and understanding more about ADL equipment.

Secondly, several papers were excluded which may have met the inclusion criteria if the information provided were clearer (outlined in Section 2.5.1). For example, ascertaining who was responsible for the assessment of ADL equipment was challenging, for example, identifying which profession or whether the assessor was a qualified or unqualified member of staff. In some cases, the 'occupational therapy service' was cited as the assessor. Additionally, several papers explored ADL equipment from a joint therapy perspective, for example occupational and physical therapy.

As highlighted in several previous sections (2.1, 2.2, and 2.4) the decision to exclude international papers presenting non-UK research was made. At the time of the decision, the inclusion of international research was considered detrimental due to the focus of this research which was on UK clinical practice. Equally, provision may have been affected by differing funding streams which in turn could have affected service user's use and opinion of the equipment they were provided with. On reflection, the exclusion of international papers may have limited the overall findings of this review of the literature. An exploration of international research methods which may have been conducive to this literature review and the main research project. The impact of alternative sources of funding for equipment may also have been proved irrelevant

and/or the consequences discussed in relation to their findings and those of this review. In hindsight, repeating the literature review to include rather than exclude international research which would meet the inclusion and exclusion criteria generally would have been appropriate and beneficial to the outcome of the review. An exploration and comparison of the implications of funding, both nationally and internationally, would also be useful in informing future research.

As such, a later preliminary screening of the four international papers highlighted in Section 2.5.2 (Wielandt et al 2006, Wynn and Wickham 2009, Krantz 2012, Meyer Larsen et al 2019) and four others selected randomly from the other 869 excluded papers highlighted several key points supporting the inclusion of international papers. As in the original literature review, the title and abstracts of the four randomly selected papers (Finlayson and Havixbeck 1992, Chiu et al 2004, Pettersson et al 2007, Cruz et al 2016) were screened for their potential relevance before the full text of all eight papers were read. An appraisal was not completed as the quality of the research was not in question at this time. Of the eight papers, five involved primary research (Finlayson and Havixbeck 1992, Chiu et al 2004, Wielandt et al 2006, Pettersson et al 2007, Cruz et al 2016, two a form of literature review (Wynn and Wickham 2009, Meyer Larsen et al 2019) and one a framework proposal (Krantz 2012). Of these, based on the inclusion and exclusion criteria provided in Section 2.4 (Table 2.1) five would have been excluded (the two literature reviews, the framework proposal and Wynn and Wickham 2009). The remaining three, Finlayson and Havixbeck (1992), Chiu et al (2004), and Wielandt et al (2006), with the exception of point 'ii' (in Table 2.1), appeared to meet the inclusion criteria. All three papers highlighted findings relevant to the context of this literature review and offered pertinent implications to and recommendations for occupational therapy clinical practice (e.g. person-centred assessment, service user perceptions of themselves and the equipment, the need for follow-up interventions and its [equipment] promotion of factors such as quality of life).

A further limitation of the review may involve the exclusion of papers related to occupational therapy practice and ADL equipment, which, may have inadvertently influenced the outcome of the quality rating process adopted in Section 2.6.2. The use of inclusion and exclusion criteria identified a small number of relevant research papers which were subsequently quality graded. This review rated three of the papers as B2, one as C2 and nine as D2. Research papers not meeting the inclusion criteria were excluded and thereby not quality graded. Literature reviews with alternative inclusion and exclusion criteria may therefore find the overall quality of the research relevant to

their reviews of a higher quality. As such, there may be papers with a high quality of evidence and a strong strength of recommendations. The exclusion of grey literature may also have resulted in a level of publication bias.

Eight of the nine studies recruited adult participants, the majority of which were aged over 60 years. Similarly, the primary reported diagnoses were narrow, with arthritis or a neurological origin dominating. Except for Goodacre and Turner (2005) the main equipment types were bathing, toileting and dressing. As highlighted above, several papers were excluded from this review some of which may have represented the broader range of equipment for ADLs such as items related to moving and handling, mobility, food and meal preparation, pressure relief, positioning/repositioning and comfort.

## 2.10 Conclusions and Recommendations

Whilst the outcome of this literature review indicated a long-term relationship between occupational therapy practice and ADL equipment, the research evidence to support this is was found to be inconsistent and sparse. As such, given the low volume and poor quality of the evidence identified and presented (see Section 2.7.1 and Section 2.7.2) this relationship between the two is not satisfactorily represented. Whilst literature which centres on utility and factors such as how many items were provided, used and over what period may be useful this is limiting in terms of the actual impact it has on the individual service user and those who may support them. Questionnaires limited to yes/no responses or those which fit on a Likert scale provide useful binary information. They do not or are unlikely to capture individual personal expression that may better capture the impact equipment may have. Understanding whether ADL equipment is seen purely as a means to function or has attached meaning may influence the decisions made by commissioners and as a consequence future practice. Overall, a robust literature review found limited and poor quality evidence surrounding the topic of occupational therapy and ADL equipment. These findings reinforced the need to conduct original research and further supported the aims and objectives of the main research project.

Of the nine studies, four reported findings which specifically indicated the benefits of equipment provision. Study 1 demonstrated a link between maintaining independence levels when using bathing equipment, Study 7 provided positive feedback which was described as useful but also essential. The benefits of equipment on quality of life were highlighted by Study 8.

Due to direct contact with participants via a questionnaire or face-to-face, in all nine cases the opportunity to explore, in-depth, the meaning behind and the impact of ADL equipment was clear. Unfortunately, this was not exercised to its full advantage. For example, little attention was granted to the actual impact of the equipment on the participants. As such, though equipment is 'useful', its actual value on quality of life and the potential overall meaning this may have is unknown. Although the nine studies met their research objectives, the information they provided to support the use of ADL equipment and the role occupational therapists play was limited. Understanding the importance individuals place on equipment, whether for purely practical or psychological and emotional reasons, would assist occupational therapists, managers, and commissioners to understand why equipment is accepted, not accepted or used in the longer term. Further research capturing the user's voice would assist in determining whether this is important in evidencing the relationship between occupational therapy practice and ADL equipment and has the strength to inform stakeholders. This knowledge may help to shape future equipment assessment and provision criteria.

The findings of this review could be suggestive of a medical rather than a social approach to exploring and supporting the evidence base. This is compounded by a focus on the utility and practicality of equipment as opposed to an in-depth exploration of the impact of equipment on the user. Whether the benefit of equipment has an effect on well-being and quality of life is currently not understood. The continued use of equipment over time is suggestive of 'something', however determining whether this is purely a functional benefit or contains elements of other beneficial qualities is yet to be explored and determined.

#### 2.11 Summary

As highlighted throughout Chapter 2, a limited volume of research associated with occupational therapists' clinical practice, particularly with reference to equipment and ADLs within UK home environments was identified. A lack of clarity surrounding the geographical origins of the research and who was responsible for the assessment of the equipment provided limited the number of papers found to be relevant to this literature review. The majority of the 13 papers included predated the 2000s, with only two found to be published after this (Goodacre and Turner 2005, McNaught et al 2016). Of the 13 papers, several presented the findings of three of the research projects presented. Due to the robust structure of the search process it is unlikely that papers will have been missed.

Due to the limited number of research projects and the repeated publications the methodologies and methods are not dissimilar. They were also found to be of poor quality. The pool of participant demographics, including ages and primary diagnosis, were as equally limited. However, it could be argued that the age groups and diagnoses involved is representative of the typical population of patients seen by occupational therapists and other health professionals.

Overall, four themes and nine sub-themes were developed during the thematic analysis process. The four themes were: Utility, Failing to Give Voice, Improving Services and Outcomes, and Quality of Life. As the first theme 'Utility' implies, the focus here was on number and types of equipment items provided and for how long they remained in use. There was also some exploration of the consistency of provision. The relationship between the environment and equipment was also examined. It found an incompatibility between some equipment items and the environment whilst also acknowledging how the physical environment could restrict or impede access within properties and thereby limit the opportunities for equipment to be provided. The poor design of equipment was also highlighted in terms of practical use and issues with safety. This issue links to the subject of the usefulness of equipment with the majority of the research conducted highlighting which of the equipment was found to be useful or not. The final sub-theme involved issues related to review and follow-up. It linked the lack of a follow-up policy to the high volume of abandoned equipment. In turn, equipment not in use was also associated with timely discharge, inappropriate provision and poor instruction related to the fitment and use of ADL equipment.

The second theme, 'Failing to Give Voice', whilst not extensive in nature, further emphasised the paucity of research related to the subject of occupational therapy and ADL equipment. It demonstrated how the volume of research in the area of interest has not grown over time. In fact it could be suggested the volume of research which fits the inclusion criteria of this literature review may have decreased. Within the 13 papers there was little recognition of the involvement of the service user in the decision making process; the exceptions were Study 1a and Study 5.

Theme three, 'Improving Services and Outcomes', explored the issue of training and instruction in more detail. It centred on the correlation between increased independence and the long-term use of equipment with detailed instruction which included enhanced opportunity for demonstration and practice. Several of the papers also enquired whether the instruction they had received was 'useful'. This theme

returned to the concept of timeliness and how, according to the authors of Study 1 and Study 2, a delay in provision had a direct impact on dependency levels. The debate between follow-up and non-follow-up continued within this theme. For example, Study 1 and Study 2 both supported the need for some form of follow-up, whereas Study 3 simply disregarded this as an ineffective use of resources. The authors of Study 3 did, however, advocate the need for an improved system of storing and delivery.

The final theme, 'Quality of Life', indirectly indicated the impact of some equipment on its users. For example, the terms independence, reliance, morale and value were used. Whereas Study 5 indicated how care giver experience can directly enhance the experiences of the equipment users. Unfortunately, the relationship between ADL equipment and quality of life was implied rather than explicit. Where reference to the concept was made, information was often presented as a percentage rather than in the words of the service users.

The implications for clinical practice are not dissimilar to the current experiences of the researcher. For example, the design of equipment versus the environment, identifying the most suitable assessment environment, timely provision, and follow-up and review remain as relevant today.

Several limitations to this literature review were identified. The most important of these is the exclusion of international research and papers which failed to distinguish who was responsible for the assessment of the equipment. The inclusion of these papers would have provided some insight into the use of and impact of equipment from a broader range of perspectives. Any anomalies and idiosyncrasies which arose, such as issues with funding, could have been discussed in context in relation to the data and information provided. The decision to exclude these papers may have been to the detriment of the review overall.

While determining the numerical 'usefulness' of equipment may be of some benefit, this type of data fails to capture the true experience of 'equipment' from the perspective of those who provide and use it. The findings of this literature review highlight the lack of robust research evidence which supports occupational therapy clinical practice in this area. Equally it demonstrates the lack of clinical and service user 'voices' in research. As such, an in-depth exploration of occupational therapy, equipment and service users which goes beyond the assignment of numbers and calculating percentages is indicated. Research which attempts to gain access to the nucleus of equipment may

provide greater insight into its 'usefulness' or its 'uselessness'. An in-depth exploration of these concepts may increase our understanding of equipment use and thereby inform future clinical practice.

## **Chapter 3: Research Methodology**

The two preceding chapters provided the contextual background to the purpose of the main research. Chapter 1 introduced, amongst others, the concepts of occupational therapy, equipment and activities of daily living. An exploration of the existing evidence base found a paucity of research much of which was of poor quality (Chapter 2).

Chapter 3 presents the rationale for the selection of a qualitative approach and Interpretative Phenomenological Analysis as the chosen methodology for the main research project. This is underpinned by the researcher's philosophical and epistemological stance. It provides details surrounding the data collection and analysis methods including the decisions behind any choices made.

The combination of reflecting on the findings of the previous two chapters and discussions with the supervisory team resulted in the decision to focus on the use of ADL equipment by service users with a long-term condition. At present, in England alone there are thought to be approximately 15 million individuals living with a long-term condition such as arthritis, diabetes and chronic obstructive pulmonary disease (King's Fund 2021). These conditions or diseases have no known cure. In addition, the decision to include all ADL equipment traditionally assessed for and provided by occupational therapists was made. Equally, given the lack of presence of 'the experienced voice', a project focussing less on experimental forms of research such as numerical measurement and statistical analysis was indicated (Braun and Clarke 2013, Creswell 2014, Privitera 2017).

# 3.1 Research Paradigm: philosophy, ontology and epistemology

The fundamental concept of 'philosophy' involves the human pursuit of knowledge. As researchers, this requires us to consider our ontological and epistemological stances, both of which are central to determining our approach to and the choice of the methodology and methods we adopt in order to conduct research. We must explore our assumptions and perspectives about how we view and position ourselves and what we believe we do and do not know about us and the world (King et al 2019).

## 3.1.1 Ontology and epistemology

Firstly, we must consider our ontological view of reality; namely do we view the concept of 'reality' as a single entity or from multiple perspectives. The view we take indicates a

preference for either a positivistic or quantitative standpoint (where there is only a single reality) in contrast to the alternative interpretivist or qualitative stance (which believes there are multiple realities). Those who align quantitatively are typically interested in the causal relationship between two elements and investigate this through measurement and statistical analysis to prove or refute a hypothesis. For example, they are interested in determining whether there is or is not a relationship between 'a' and 'b'. Alternatively, with a qualitative viewpoint, there is no hypothesis. Qualitative researchers therefore aim to seek out participant's individual understandings of their reality and perspective of meaning. Qualitative research invariably involves direct interaction, through observation and talking, to seek out individual experiences of an event. The qualitative researcher's interest lies amongst the relationship and meaning participants place on 'a' and 'b' and accept that their reality of these and what lies in between is unique to them.

Secondly, we identify our epistemological stance. This requires us to consider how best we can source or gather the information or knowledge we seek. With a quantitative positivistic approach, data is usually gathered numerically and tested using a range of statistical tests to prove or disprove theory linked to a hypothesis. This is considered as a top down or deductive approach as understanding and knowledge is derived from the hypothesis based on pre-existing theory. In contrast, the qualitative interpretivist researcher is interested in understanding a phenomena or event. They actively place themselves in the company of the participants before then attempting to interpret and inject meaning into their observations and transcript data. This bottom-up inductive approach seeks to generate understanding or theory from the collected data (Waters and Mehay 2010, Rehman and Alharthi 2016).

As an occupational therapist and individual, I believe situations or contexts influence and impact my perception of reality. Bearing this in mind alongside my ontological and epistemological perspectives I considered how best the primary research question could be asked and answered:

'How do service users and occupational therapists in the United Kingdom experience equipment for activities of daily living?

I concluded that in this instance, my 'reality' was viewed from multiple perspectives and epistemologically my interests lay in understanding how people experienced and made

sense of things. I therefore selected a qualitative approach to assist with addressing the main research project.

#### 3.1.2 Selection of a qualitative approach

The inductive or theory generating approach of qualitative research involves the development and interpretation of themes which are identified and built upon during the process of data collection and analysis (Braun and Clarke 2013, Creswell 2014). This approach aligned with the ethos of the research question and as such was considered preferable to that which tested existing theory (Agee 2009, Richards 2015). Furthermore, the themes generated through qualitative research facilitates a more indepth detailed account of an identified issue or problem which unlike quantitative studies is not intended to represent whole populations (Flick 2014). Invariably, qualitative research uses the words it collects as the foundation of understanding experiences (Finlay 2011). It was therefore important to ensure the appropriate selection of methods based upon the ideals and assumptions of the researcher and the topic under study (Flick 2014).

The interpretivist viewpoint of a qualitative approach involves the perception that as individuals we are interested in our world and are eager to understand the meaning behind the complexities of how we live, work and play (Creswell 2014). This perception accepts the suggestion that each individual, who may have witnessed or participated in the same or similar event, is likely to describe their experience differently to others (Braun and Clarke 2013, Privitera 2017). Therefore, whilst the participants in this research project experienced the same phenomenon – provision and use of ADL equipment – their understanding and insight is unique to them. The concept of attempting to begin to understand the meaning individuals consciously or subconsciously assign or associate to ADL equipment appealed to the nature of this research project.

Historically, within health and social care, the research field has been dominated by quantitative experiments and investigations. This domination was fuelled by the belief that qualitative research was unscientific in nature, a view some believe continues to be maintained today (Braun and Clarke 2013, Flick 2014). Prior concern with the poor understanding of the contribution qualitative research could bring is highlighted in the literature (Jones 2007). As such qualitative research was referred to as a "soft science" (Denzin and Lincoln 2011; Usher and Jackson 2014, p192). However, there is growing support for qualitative research linked to an increased awareness of the recognition of

individual experience and meaning to inform our understanding of issues that are not easily captured by larger test-based approaches (Flick 2014, Thomas and Magilvy 2011). This growing understanding fitted comfortably with the nature of this research project which explored the in-depth experiences of the individual. The opportunity to reveal new insight into the topic of occupational therapy practice and ADL equipment was paramount. Once the philosophical approach was identified, the selection of an appropriate methodology was equally as necessary.

## 3.2.2 Choosing a methodology

Once qualitative research was identified as the overall framework for this project, the next important decision was to identify a suitable methodology. Prior to commencing this element of the research I had a basic awareness of methodologies such as ethnography, grounded theory and phenomenology. For example I was aware that ethnography was interested in cultures and society and grounded theory in emerging theory derived from new evidence; whereas phenomenology was about 'experience' (Agee 2009, Carter and Lubinsky 2016, Flick 2014, Privitera 2017). Based on this simple level of understanding, my instinct was leading me toward phenomenology. However given my overall poor knowledge and understanding, to best inform the decision making process I returned to the theory surrounding all three so as to enable me to make the most appropriate selection. Once all three had been explored in depth, both ethnography and grounded theory were subsequently dismissed.

This decision was based on the understanding that neither of these two methodologies aligned with the intended purpose of this research which was interested in the 'individual experience'. For example, ethnography concerns itself with environmental adaptation, social interactions and group beliefs which traditionally requires researchers to immerse themselves as a participant within the social or cultural environment under study (Dutta 2014, Flick 2014, Privitera 2017). As my research was interested in the participant as an individual and their singular personal use of equipment, ethnography would have clearly been a poor choice. Furthermore some ADL equipment is often used in private contexts and environments not as part of a social or cultural activity. When comparing phenomenology and grounded theory, the former explores the 'lived experience' via carefully and systematically constructed research (Usher and Jackson 2014) which provides insight into phenomena rather than the latter which focusses on theory generation which attempts to explain or control events (Stanley 2006, Finlay 2011, Bowling 2014, Usher and Jackson 2014). Both methodologies involve heterogeneous theoretical sampling until data saturation is

reached (Breckenridge and Jones 2009, Davoudi et al 2017). This concept was in opposition to the premise of this research project which was to study the experiences of a homogenous group, using their own individual descriptions to explore the phenomena. Thereby, as phenomenology is interested in the research participants' experience it was chosen as the most suitable methodology.

In essence, phenomenology explores the conscious experiences of an individual (Privitera 2017) with the researcher then offering the views and voices of the participants as findings (Carter and Lubinsky 2016). It is often described as 'transformative' due to it 'giving voice' to those who have experienced a phenomenon, before assisting them to focus on and attempt to make sense of their experience (Finlay 2011). Unlike other philosophical approaches, phenomenology recognises and accepts the same phenomena are experienced differently by individuals. As such, participants who experience an event, in this case equipment provision by occupational therapists, will experience their own reality of that event in ways that reflect their own perspective. In other words, phenomenology is an idiographic approach to understanding an individual's perspective of an event. Furthermore, the alliance of values, skills and common interests between phenomenological research and clinical practice, such as occupational therapy, was an important factor when considering the choice of an appropriate methodological approach (Finlay 2011).

Finlay, an occupational therapist, highlighted some of the parallels between clinical practice and phenomenological research (2011). These included amongst others reflection, empathy, interviewing skills, and openness (Finlay 2011). As an occupational therapist themselves, the researcher considered the phenomenological approach as highly relevant to their own research project which sought to explore the experiences of its participants. Phenomenological research is often selected to explore the everyday lived experiences of individuals without aligning the event or experiences to controls and variables (Giorgi and Giorgi 2013). Participants who have experienced the same event or phenomena are purposefully sought by researchers, who through the process of analysis, then endeavour to elicit its meaning or 'essence' (Giorgi and Giorgi 2013). Qualitative data analysis is described as a repeatedly close and questioning engagement with the text which is organised into units. These in turn are transformed into concepts or themes which are then connected descriptively to provide an in-depth commentary of the experience

Within the allied health professionals, including occupational therapy, there is a professional expectation to engage in a range of forms of research activity. The purpose being to source, evaluate and implement evidence relevant to clinical practice and add robust meaningful research outcomes to the evidence base (RCOT 2021a; 2021b). It is widely acknowledged within the profession of occupational therapy and others, that simply believing our practice is safe and effective is no longer acceptable (Finlay 2011). As identified in Chapter 2, a good quality evidence base for occupational therapy and ADL equipment within the UK is currently lacking. The RCOT (2021b) recently published their priorities for research within the profession. When examining their top 10 priorities, clear parallels between them and the objectives of this main research project are evident in the statements they issue. For example, words and phrases such as "impact on daily life", "person-centred", "effective and cost-effective" "self-management" and "reducing hospital admissions" (RCOT 2021a, p2) correlate with the objectives in Section 1.7, and the findings and discussions generated within this thesis (Chapter 4 and onward). Whist there are a range of research methodologies available, as highlighted above, the method selected should reflect the topic of research under study. The use of qualitative research was supported by the findings and recommendations of previously conducted research such as that of Ballinger et al (1999) who advocated how quantitative research may be suitable in some areas and qualitative in others. Ballinger et al (1999) used data collected as part of a wider RCT to explore stroke-based therapy interventions. Whilst accepting the results associated with the RCT were relevant and informative they implied that a mixed approach which included qualitative methodology would have enhanced the overall findings by capturing a broader range and depth of information.

Whilst I had some knowledge and awareness of phenomenology, interpretative phenomenological analysis (IPA) was a completely new concept. IPA only became known to me during my exploration of phenomenology as a research methodology and discussions with my PhD supervisory team who expressed their previous relationships to a range of qualitative methodologies. IPA as the chosen methodology for this, the main research project, is described in detail in Section 3.2.3 below.

## 3.2.3 Interpretative Phenomenological Analysis as the Chosen Methodology

Interpretative phenomenological analysis is a form of hermeneutic phenomenology which has experienced increased interest since the mid-1990s (Smith 1996, Smith et al 2009, Finlay 2011). It comprises of three philosophical concepts (Smith 2011). The first, phenomenology was introduced in the preceding section (3.2.2); the remaining

two are: hermeneutics and idiography. These are discussed in greater detail during the remainder of this section.

Whilst continuing to be used in the field of psychology, for which it was first developed, IPA is increasingly adopted by other health and social care professions such as physiotherapy and occupational therapy (Finlay 2011, Smith and Eatough 2007). IPA explores the meaning attached to individuals lived or living experiences (Finlay 2011, Smith and Osborn 2015), which according to Smith et al (2009) is heightened when the phenomenon is seen as 'significant'. Whilst IPA aims to discover the meaning of individual experiences, it also seeks to explore variances (divergence) and parallels (convergence) between individuals experiencing the same event (Smith et al 2009).

IPA is described as dynamic, inductive, iterative, emergent, exploratory, and fluid which observes active involvement by the researcher (Clarke 2009, Finlay 2011, Smith and Osborn 2008). As a hermeneutic approach, IPA acknowledges the experience of the individual as unique, and therefore the expectation for others to understand or know the experience is not anticipated (Cronin-Davis et al 2009, Finlay 2011). However, IPA positions the researcher such that an attempt to understand the event or phenomenon from the individual's perspective is made. It does involve a 'long arm' stance to enable the researcher to question and probe the individual's perspective (Smith and Eatough 2007). IPA is interested in exploring what we as humans encounter and experience. As a researcher, we are in a privileged position to rationalise how our participants see and attach meaning to things. We can access the core experiences of our participants and examine the essence of the phenomena they report. As the researcher our role is to interpret and convey 'experience' whilst ensuring we balance the participants and our (researcher's) voices.

In addition, compared to other methodologies such as those introduced in Section 3.2.2, IPA accepts and expects a relationship between participants, the researcher and their prior experience, knowledge, and conceptions to have some effect on any interpretations made (Clarke 2009, Cronin-Davis et al 2009, Finlay 2011, Smith and Eatough 2007). Equally however, a limitation of IPA highlighted by Reynolds (2003) and Cronin-Davis et al (2009) involves the researcher inadvertently imparting their own interpretation of an event upon the analysis process despite attempting to maintain a co-constructive relationship between themselves and the data. Within both phenomenology and IPA, there is an expectation that researchers acknowledge prior experience and preconceptions of a phenomena. However, while phenomenology

expects preconceptions to be 'bracketed' or put to one side so as not to affect the shape or outcome of the research, IPA accepts it is impossible to completely 'bracket' or create the 'phenomenological attitude'. Within IPA it is acceptable to use preconception as part of the analysis process provided it/they are recognised (Smith et al 2009).

IPA differentiates itself from other hermeneutic approaches by directing its interest toward making sense of an individual making sense of their own personal experience or experiences of themselves or the social world (Finlay 2011, Smith and Eatough 2007, Smith and Osborn 2015). This double hermeneutic process is described as:

"The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith and Osborn 2008, p53).

According to Smith and Osborn (2015), IPA utilises both questioning and empathic hermeneutics to understand individual perspectives. As such the nature of IPA allows for text to be critically questioned and therefore highlight issues the participants themselves were unaware of. In addition, the researcher is attempting to understand the participant's experience of the event or phenomena (Smith and Osborn (2015). Successful IPA observes a constant grounding within the text despite the analysis process involving the researcher's own layers of interpretation (Finlay 2011). During analysis, the analyst is expected to shift between the 'whole' and 'part' of the phenomena to try and make sense of its meaning. For example, to understand 'a word', one must consider this in relation to the rest of the sentence. However, to also understand the sentence it is necessary to understand the individual words and how they fit together to then gain an understanding of the meaning of the sentence (Smith et al 2009). It is also important to approach the process of this close analysis iteratively by shifting forward and backward between and across how we explore the words and sentences. As the researcher immerses themselves within the analysis, their interpretations become deeper as they attempt to intimately engage with the experiences of the individual they are studying. This process observes the researcher attempting to understand the meaning of the participant's experience and then endeavour to make sense of it; otherwise, a 'double hermeneutic' (Smith et al 2009).

The third concept, idiography, focusses on how experiences are understood from a contextual perspective. To achieve this, the researcher follows a systematically robust approach to gather data from a small, sometimes singular, purposively selected

homogenous sample (Smith et al 2009). As IPA uses a small sample to explore the phenomena of individuals, it recognises its findings are not generalisable to the wider population. Its findings are however considered to be transferable to others within a wider population (Smith and Osborn 2015).

Several important considerations informed the overall selection of IPA as the preferred methodology, particularly regarding the analysis process. For example, both thematic analysis and descriptive phenomenology were discounted. In the case of thematic analysis, though it involves some level of interpretation it is often described as 'surface level' and as such is generally not as in-depth or detailed as is expected with IPA. This approach would therefore have failed to capture the intended depth and essence of this main research project. Similarly, descriptive phenomenology was also discounted as its focus is a rich description of the participant's experiences with limited attempt to interpret and derive meaning from the data (Braun and Clarke 2013, Matua and van der Wal 2015). This decision was further supported during discussions with the PhD supervisory team where I was continually drawn back to IPA as I was interested in more than simply describing the data I collected. Equally, I believed neither of these approaches would do justice to the time given by any prospective participants.

As an occupational therapist, therapy outcomes centre on service user's health, wellbeing and quality of life in relation to how they can live their lives. They are however typically based on collecting data which is collated numerically to identify directional change between improvement and decline in physical or mental health and well-being. Whilst this approach to understanding impact and outcomes may be driven by and satisfy stakeholders and commissioners, they do not capture the underlying truth of the phenomena. The concepts of phenomenology, hermeneutics and idiography both individually and collectively encompassed the intended position of exploring the phenomena of equipment for ADL. In addition, my personal and professional interest in the 'lived experience' signposted a natural pathway toward IPA as the methodological choice of this research. The purpose of the main research project is to explore the meaning of the lived experience with a small number of purposively selected individuals. The use of IPA as a research methodology will capture unique data which will inform stakeholders and commissioners of the true impact of ADL equipment. It will also provide the opportunity to consider outcome measures which are sensitive to the intervention and purposeful in informing future practice.

#### 3.2.4 Exploring the Evidence: Interpretative Phenomenological Analysis

According to Clarke (2009), the occupational therapy profession underwent a period of change which, once completed, led to a clearer focus on occupation and its connection to health and well-being. Integral to this was the need for occupational therapists to use research methodologies which highlighted, emphasised, and demonstrated this relationship by capturing rich data and presenting in-depth analysis (Clarke 2009, Cronin-Davis et al 2009). IPA is identified as an appropriate and relevant methodology for achieving this due to its philosophical underpinning of focussing on, exploring, and interpreting the actual experiences of the participants (Clarke 2009). Within health and social care this enables the researcher to examine in depth and detail the experiences of service users, their carer givers and organisational employees which may result in service improvements (Clarke 2009). In addition, the intent of IPA to 'understand' experiences aligns itself to occupational therapy and its approach to patient centred care, therefore assisting with the development of therapeutic interventions (Clarke 2009, Cronin-Davis et al 2009). The use of IPA by health care professions is widely promoted within the literature (Smith 2004, Clarke 2009, Cronin-Davis et al 2009). As acknowledged by Smith (2011), the popularity of IPA has increased since its inception both within and external to health and social care services and organisations. Consequently, the volume of published literature has grown in parallel to this. For example, according to Flowers (2017) the number of IPA publications increased to 2240 in 2014 from eight in 1996.

A thorough search of the literature was conducted to explore the use of IPA as an appropriate research methodology within health and social care and to support its use by occupational therapy researchers. This process revealed a wide body of IPA-related research which justified its use by demonstrating its versatility whilst also highlighting its limitations. With regard to health and social care papers were found to represent a broad range of professional backgrounds including therapy and social work and areas of clinical practice including mental health (Prior and Conway 2008, Dickson et al 2009, Maddock 2015), preceptorship (Marringer and Jensen 2014), undergraduate education (Mellor et al 2013), nature based rehabilitation (Pálsdóttir et al 2014) social eating (Absolom and Roberts 2011), pain management (Hawtin and Sullivan 2011) and work life balance (Clouston 2019).

In relation to occupational therapy practice there was an equally extensive range of IPA based published research. For example, Pettican and Prior (2011) demonstrated a link between occupational engagement, health, and well-being during the transition from

employed work to retirement. Wensley and Slade (2012) explored walking as a meaningful occupation in healthy adults whereas cycling as a therapeutic occupation was the focus of Feighan and Roberts (2017) research. Blank et al (2016) and Newport and Clarke (2020) examined the use of the Occupation Matters Programme, while Clarke et al's (2018) participants shared their experiences of meaningful activity whilst inpatients on an acute medical ward. Other non-specific subject areas of research were, cross-dressing (Curtis and Morris 2015), arts and crafts (Timmons and MacDonald's 2008, Reynold's 2009), recruitment (Farrell and Bryant 2009), social inclusion (Smyth et al 2011), developmental delay (Payne and Ward 2020), dysexecutive syndrome (Preston et al 2014), the concept of play by disabled children (Graham et al 2019), role-emerging placements (Clarke et al 2014; 2015b), work life balance (Clouston 2014), emergency care (James et al 2018) and homelessness (Cunningham and Slade 2019). With specific regard to equipment, May and Rugg (2010) explored the impact on the quality of life and occupational performance of 12 electrically powered indoor outdoor wheelchair users. Although only a single paper was found to represent equipment-based research, the overall volume and variety of topics indicates IPA is adaptable to the area of research under study, including ADL equipment.

A modified review form developed by the researcher was used to evaluate occupational therapy related literature thus enabling subject content and attention to the IPA approach to be examined. The form is based on the Critical Review Form – Qualitative Studies (Version 2.0) (Letts et al 2007b, with additional guidance from Elliott et al (1999), Smith et al (2009) and Yardley (2000). In addition, the 'quality evaluation guide' provided by Smith (2011) was used as a basis for determining the quality of the IPA papers. All of the papers whether occupational therapy related or from a health and social care perspective focused on the lived experiences of the participants. As may be expected, and similar to Section 2.7.1 and 2.7.2 of the literature review conducted in Chapter 2, the level of detail provided, particularly surrounding the methodology and ethics, varied.

The papers explored concerned themselves with a range of issues related to both physical and mental ill health which demonstrates the utility of IPA as an appropriate methodology for occupational therapy practice research. Overall, this exercise highlighted to the researcher several benefits and limitations to using IPA as a research methodology. It also evidenced the breadth and scope of IPA as a relevant

methodology within a range of work contexts and sectors including health and social care and more specifically occupational therapy.

## 3.3 Study Design

Section 4.5 presents the process followed during the main research activity of this project; this includes the rationale for any decisions made. It also provides context and perspective to the findings chapter.

## 3.3.1 Sample and Participant Recruitment

As previously discussed in Chapter 1, my interest in the patient's use of equipment for ADL developed from a personal perspective and a professional curiosity whilst in clinical practice. As such the original concept of this research project involved only the patient's experience of this phenomenon. However, as I explored the literature in more depth (Chapter 2) and reflected more deeply on my clinical practice experiences the project evolved into one exploring a range of perspectives. This, in combination with discussions with the research supervision team resulted in the decision to include occupational therapists with direct clinical experience of the assessment and provision of equipment and those who manage them. Therefore, three distinct phenomena were identified – the experiences of equipment from the perspectives of the service user, clinicians and managers.

Within IPA, a homogenous sample is expected which by design is then representative of the phenomena under study; in other terms an idiographic approach which neither expects many participants. Sampling is purposive via the researcher's own contacts, gatekeeper's or the process of snowballing (Smith et al 2009). According to Smith et al (2009), the number of participants recruited and interviews conducted is dependent on the context of research and the experience of the researcher/s. In the case of a Philosophy Doctorate (PhD), a larger sample size is anticipated compared to other levels of research which may involve three to six participants; there is no specific number of recommended participants or number of interviews for an IPA PhD research project. Equally, though not literally prescribed, PhD researchers are strongly encouraged to complete "three self-contained but related studies" (Smith et al 2009, p52) which matched the intention of this main research project to interview the three distinct but related groups of participants. To ensure a sufficient number of participants were recruited and to gather quality data it was agreed by the researcher and their

supervision team that a maximum of 10 participants per group would be interviewed: up to a maximum of 30 overall.

The sample for this main research project comprises of three sub-groups.

- i. Nine managers and leaders responsible for staff/services who provide equipment.
- ii. Ten occupational therapists responsible for equipment provision.
- iii. Five adult NHS patients and two members of a local support group all with a long-term condition who have experienced occupational therapy in relation to equipment assessment and provision.

During the process of gaining ethical approval, members of a local support group became aware of the research project during a readability and suitability exercise requested by the NHS REC Research Committee. This resulted in two members of the support group being interviewed and accounts for the total number of service users overall who were interviewed.

#### 3.3.3.1 Participant Sub-Group 1 – clinical leaders and managers

Upon request, and in line with the ethical process previously outlined, a gatekeeper employed within the relevant NHS Trust provided a list of clinical leaders and managers. I duly contacted them by email inviting them to participate in the research. It became apparent, however, that a number of those contacted were unlikely to have direct involvement in equipment assessment and provision. An informal discussion with a clinical leader within the Trust (which did not disclose the names of those contacted) highlighted that during the ethical application process an organisational restructure had taken place. The outcome of this restructure had resulted in the roles and responsibilities of prior managers and clinical leaders changing. As such higher banded occupational therapists were now in a position that incorporated a greater clinical leader or manager role. To have not received consent to participate from senior management was disappointing as it had been hoped their input would have added additional insight into the phenomena of occupational therapy practice and ADL equipment. Addressing this in future research would be both appropriate and beneficial in understanding decision making from a senior management perspective. This information would inform all parties of the decision making and clinical reasoning processes involved in senior management and occupational therapists practice. This would result in a greater understanding of the factors affecting practice from both perspectives with the effect of enhancing relations and reducing conceptual divide.

I therefore re-contacted the gatekeeper and requested a further list to include occupational therapists with the required role characteristics being sought. My decision to approach the gatekeeper for the second time was supported by the responses I received from both the initial and secondary round of emails. Of the 12 emails from the original list, three indicated they felt unable to participate as they were not occupational therapists by profession, one declined to participate as they considered they had not been in post for a sufficient period and eight did not respond. In contrast, the number of respondents to the second set of emails was greatly improved, eight of which indicated a clinical leader/manager role and who subsequently consented to be interviewed. A clinical leader, not included on the primary or secondary list, later provided consent after requesting information about the research via a colleague. One respondent declined as their role no longer involved a clinical caseload, and two consented to participate as part of sub-group two. In total, nine occupational therapists with responsibility for managing/leading other occupational therapists consented to participate. Due to the nature of their role, the nine participants with a manager/leader role were also practicing occupational therapists with a clinical case load of their own. Due to their dual experience of equipment assessment and provision, as a researcher I found this enhanced the content of their interviews. This topic is explored reflexively during the analysis process [Chapter 4] and within the discussion chapter [Chapter 7] of this thesis. Given the nature of their roles, from this point forward members of subgroup 1 will be referred to as clinical leaders.

#### 3.3.3.2 Participant Sub-Group 2 – occupational therapists

Two participants from sub-group one were asked to provide the contact details of prospective recruits relevant to sub-group two. To widen the diversity of potential recruits to sub-group two, clinical leaders from differing clinical backgrounds and localities within the Trust were approached. Though there was some crossover of names, the list was wide-ranging in terms of context and locality. Had the response been poor, a snowballing effect through contact with other occupational therapists from sub-group one would have taken place. In total 37 emails were forwarded to prospective participants in this sub-group. Of these, eight occupational therapists consented to be interviewed. When combined with the two who initially responded to the sub-group one request for participants, a total of 10 consented to be interviewed.

3.3.3.3 Participant Sub-Group 3 – NHS patients and support group Similarly, to the recruitment process for sub-group 2, I approached two occupational therapists who agreed to identify potential NHS patients. In time I extended this to include two other occupational therapists from sub-group two. The process for recruiting into this sub-group was designed such that the occupational therapists identified prospective participants who consented for their contact details to be forwarded to me. However, I found that those interested in the research preferred to receive the participant information form directly from the clinician and return this to me circumnavigating the need for them to be sent the form. Having referred to the advice provided by the HRA Yorkshire and The Humber – South Yorkshire REC it was considered unnecessary to seek an amendment for this minor change in the recruitment process. In total eight participant information forms were returned. However, five ultimately consented to participate. Of the three who did not go on to provide their consent, one declined to participate, one could not be contacted and the third had not received their equipment. (The latter respondent was encouraged to contact the prescribing occupational therapist to enquire about the expected delivery times of their equipment).

As previously discussed in Section 3.3.1, two of the participants in this sub-group originated from a support group. Upon returning the participant information sheet and consent forms [intended for NHS patients], several members of the support group indicated their interest in participating in the research. This resulted in my approaching the York St John University Research Ethics Committee for retrospective approval to be added to the original application; this was duly granted. I then forwarded copies of an amended participant information sheet, the wording of which reflected the support group rather than NHS patients as participants and received two responses. When contacted, both individuals agreed to be interviewed, providing written consent at the point of their interviews. Unfortunately, due to a change in circumstances two other members of the support group who had expressed an initial interest were no longer in a position to participate and thereby withdrew their consent to be interviewed.

In line with the ethical process, prospective participants were to be given seven days in which to decide whether to participate [return their consent slips] in the research before a reminder was sent. This process worked well in relation to sub-group 1 and 2. However, with sub-group 3 [NHS patients], their preference was to complete the consent section of the participant information sheet, copies of which were available from the clinician, and forward them directly to me, the researcher. As a result, the

number of information sheets provided, and to whom, was unknown which prevented reminder forms to be sent.

All the participants were informed of their right to withdraw from the study up to two weeks following their interview without having to provide an explanation. A timescale of two weeks was considered appropriate as it was anticipated the interview would have been transcribed and early analysis commenced within this timeframe. None of the participants subsequently withdrew from the study.

# 3.3.2 Inclusion Criteria

In line with general qualitative methodological guidance, all of the potential recruits to the project were identified purposively using a clearly defined set of inclusion criteria as follows:

# Participant sub-group 1 – clinical leaders

- i. To be able to consent to interview written/signed.
- ii. To be able to communicate in English.
- iii. Have responsibility for occupational therapists who have completed recent interventions involving the assessment for or provision of equipment for activities of daily living within the home environment.
- iv. To be able to participate in an interview.

# Participant sub-group 2 – occupational therapists

- i. To be able to consent to interview written/signed.
- ii. To be able to verbally communicate in English.
- iii. Have completed recent interventions involving the assessment for or provision of equipment for activities of daily living within the home environment.
- iv. To be able to participate in an interview.

# Participant sub-group 3 and 4 – NHS patients and support group members

- i. To be able to consent to interview written/signed.
- ii. To be able to verbally communicate in English.
- iii. Have received an occupational therapy intervention involving the assessment for or provision of equipment for activities of daily living within the home environment.
- iv. To be able to participate in an interview.
- v. Be aged 18 years or over.

vi. To be eligible for an occupational therapy assessment involving equipment for activities of daily living.

Due to the phenomena involved in this research it was important that the participant groups were familiar with occupational therapy and equipment for activities of daily living. As such, and in line with IPA methods, prospective participants were selected to enable the formation of three homogenous NHS sub-groups. In the case of the two support group members, whilst they were not recruited directly through the NHS, they did meet the inclusion criteria, self-selecting themselves based on the information provided within the participant information sheet.

## 3.3.3 Ethical Considerations

The importance and purpose of gaining ethical approval by the appropriate organisations relevant to research is well documented throughout the literature. Seeking and gaining ethical approval ensures the research has effectively considered any potential risks and burdens to ensure beneficence and non-maleficence is achieved (Hickson 2008, Seidman 2019). This main research project consulted and is supported by guidance provided by several organisations who promote best practice in research. These included but were not exclusive to the UK Research Integrity Office (UKRIO 2009), the WHO (2011) and the COT (2015a; 2015b; 2016d). Equally, documents and policies produced by the relevant research institute such as the 'lone working policy' were closely adhered to (Northern Lincolnshire and Goole, NLAG 2012: York St John, YSJ 2012; 2016).

The York St John University REC, the NHS REC via the Integrated Research Application System (IRAS) and the NLAG RDD granted approval to proceed with the interview element of the main research project in February 2016, January 2017 and March 2017 respectively. Copies of these documents can be found in Appendices 1, 2 and 3 (7901102\_Harrand\_23022016; 16//EE/0404, IRAS ID: 203862 and NHS approval letter dated 28<sup>th</sup> March 2017).

As previously stated earlier in this section, additional approval was later granted by the York St John University REC and the Support Group Co-ordinator prior to interviewing participants recruited from a Parkinson's Disease Support Group. The research conducted throughout this main research project adheres to the approved proposals submitted to the University and NHS ethics committees. This includes the submission of an annual progress report to the Main Research Ethics Committee. Due to the nature of the interviews, consideration was afforded to participants (particularly the service users) who may have become distressed during their interview and as such this issue was addressed in the REC ethics application. The solutions included pausing or ending the interview and providing contact information for the Patient Advice and Liaison Service, the Samaritans and condition specific charitable/support organisations. Members of staff who required support would be advised to approach their supervisor or manager and any other appropriate service/s within the Trust.

The scientific quality of this research project contributes new knowledge to the existing evidence base surrounding the provision and use of equipment for activities of daily living, with an emphasis on that assessed for and provided by occupational therapists. This includes the perspective of the individuals using the equipment, those who assess for and provide it and those with the responsibility for managing these individuals. The use of information sheets, consent forms and interview schedules supported the research proposal and the conduct of the research itself by providing participants with information relating to the purpose of the research, confidentiality, informed consent and the right to withdraw. Attention was also given to data storage, the destruction of raw data and the dissemination of the research findings. Four versions of the participant information form and three interview schedules were developed to represent the three participant sub-groups, whereas one consent form was used. An example of a participant information sheet can be found in Appendices 4. Whereas copies of the interview schedules for each participant sub-group is summarised in Section 3.3.6, Table 3.1.

### 3.3.4 Consent

Prior to consenting to participate, the design of the study enabled prospective participants to express their interest in the research by signing and returning a copy of the participant information form specific to their potential role in the research [Appendices 4]. As such, four participant information forms were developed, one to represent each of the three sub-groups and including those approached via the support group. Once received, the respondents were contacted by telephone to confirm their continued interest and, if appropriate, an interview appointment was agreed at a place and time convenient to them. All the participants provided informed written consent just prior to the commencement of their interviews, a generic consent form was used for this purpose (Appendices 5).

Following the approved recruitment process outlined above (Sections 3.3.1 and 3.3.2), the clinical leaders and occupational therapists were approached and responded via email, whereas the service users were provided with their versions of the participant information form face-to-face by a clinician or the support group gatekeeper respectively. The telephone call to arrange an interview was conducted in person by the researcher. As an occupational therapist with experience of determining an individual's capacity and capability of providing informed consent, the researcher is satisfied all the participants interviewed were able to make an informed decision as to their understanding of the research project and their ability to participate at the time of interview. Tacit knowledge and clinical experience of the Mental Capacity Act 2005 (Great Britain. Parliament 1999) and fatigue supports this rationale.

### 3.3.5 Confidentiality and Anonymity

Given the well-documented imbalance of male to female occupational therapists, gender neutrality was considered an important factor in this research project. As such, to ensure all consenting participants remained anonymous they were assigned an unrelated gender-neutral pseudonym. The decision to supplement anonymity was further supported using 's/he' when referring to the gender of occupational therapists within the transcript extracts used within this thesis. The need to use s/he was limited as far as practicable by referring to the participant's pseudonym or the term 'therapist'. Assuring participants of their anonymity was also an important element of the interview process to encourage an open and honest dialogue. Attention to maintaining anonymity continues throughout the thesis and beyond, for example during the dissemination of its findings and recommendations. Whilst the anonymity of the service users is as important, the need for gender neutral pseudonyms was not necessary. As such, they are referred to as he or she and non-identifiable pseudonyms were used.

Personal data, such as participant names and contact details were always kept to a minimum and are stored securely in a locked cabinet when not in use. Similarly, all audio recordings and electronic data are stored on password protected devices (including encrypted USBs) which in turn are stored securely in a locked space when not in use. All the audio recorded data were transferred to a secure electronic storage device as soon as practicable following interview. A password protected computer and the Olympus AS-2400 transcription kit was used during the transcription process. A list containing a coded number linked to their pseudonym is stored on an encrypted password protected USB separate to the recordings and transcripts. This process maintained anonymity whilst also providing the capacity to trace participants and their

data had they decided to withdraw from the study within the allocated two week time frame. Whilst Smith et al (2009) suggested the impossibility of maintaining confidentiality, all reasonable efforts have been made or adopted to achieve anonymity.

In addition, to ensure adherence to the NHS Trust and University lone working guidance, confidentiality was maintained by sealing participant information in individual envelopes which were presented to a 'buddy' prior to any planned interview visits. The date, time and anticipated length of interview was made visible on the face of the envelope. The name, address and contact number of the participant remained sealed in the envelope. As a result of this process, the participant details would have become known to others had concerns about the researchers' safety arisen and an envelope opened. The envelopes and their content were destroyed immediately following the interview.

In line with the active research process, copies of the consent forms, any email correspondence and pseudonymised paper-based transcript data remain in secure storage, inaccessible to others; the key is stored separately. Adherence to the Data Protection Act 1998 (Great Britain. Parliament 1998), since superseded by the Data Protection Act 2018 (Great Britain. Parliament 2018) and the General Data Protection Regulation 2018 (Great Britain. Parliament 2018), has been maintained throughout.

# 3.3.6 Data Collection

As a novice researcher several texts including Smith (2008), Smith et al (2009) and Finlay (2011) have proved invaluable in helping my understanding of IPA and how to plan and conduct a research project. Therefore, as can be expected with IPA research, prospective participants were sought who had experienced a similar event or phenomena and who were able to provide an individual account of their experiences. In this case, contact with or as an occupational therapist and ADL equipment.

The semi-structured interview schedules (Section 3.3.6) were based upon and developed alongside the guidance provided by Smith et al (2009) and feedback from the supervision team. Observations made during the literature review (Chapter 2) were considered during the development of the interview schedules. The questions at the beginning of the interviews were designed to elicit relevant information whilst also endeavouring to ease any participant anxieties. The questions were intended to encourage the participants to describe or 'tell their story' of their experiences of occupational therapy and ADL equipment. The flow of questions was designed to

follow the principles of a therapy-based intervention or interaction. The open design of the interview questions was intended to encourage the participants to give an account of their experiences which following the analysis process would provide an opportunity to address the research question (Smith et al 2009).

When designing the interview schedules and process, the logical order was to approach the clinical leaders first, followed by the occupational therapists and then the service users. However, given the unforeseen delays in receiving the NHS ethical approval and the complexity of clinical practice, including capacity and availability, except for the five NHS recruited service users the intended order of interviews was disrupted. The two support group participants were interviewed first followed by a mixture of the clinical leaders and occupational therapists. It is noted however that the majority of the clinical leaders were interviewed toward the start of the process and the occupational therapists toward the middle, and before the five service users recruited via the NHS. The decision to conduct the interviews as the opportunity arose ensured the participants were able to participate at a time convenient to them which otherwise may have resulted in lost opportunities.

Table 3.1 below, represents the interview schedules for each of the sub-groups. Prompts were used, and where required, adapted or additional questions were included within the interviews themselves dependent on the direction and the responses provided by the participants. An advantage to the delay in gaining NHS ethical approval was the opportunity to pilot the interview schedule with the two support group members. Conducting the interviews enabled me to review the order and appropriateness of the questions and gain some experience of interviewing participants. Whilst practicing as an occupational therapist and thereby used to 'interviewing' service users I was mindful that research-based interviews were likely to be different. Without belittling the participants and their data, the two interviews were an opportunity to practice my interview technique. Due to their quality, identified during the interview and analysis, both were included and reported as part of the service user sub-group in Chapter 6.

Q	Clinical Leader	Occupational Therapists	Service Users
1	Can you describe your role in relation to equipment and its provision?	Can you tell me generally about your role as an OT?	Can you tell me about your condition?
2	Can you describe how equipment affects the patient?	Can you describe how equipment provision fits within your role?	Can you describe how your condition affects you?
3	In relation to the assessment of equipment, can you describe what factors are important or not so important?	Can you describe the role of equipment in relation to your patients?	Can you tell me about what impact this may have on you and your family?
4	What do you feel are important or not so important in relation to the equipment provided?	Can you describe the impact of equipment on your patients or their families?	Can you tell me about your experience/s of OT?
5	Can you describe how you believe equipment provision fits within the role of OT <sup>1</sup> ?	Can you describe how the equipment affects your patients?	Can you tell me which type/s of equipment you have been provided with – statutory? Have you privately purchased any equipment?
6	Is there anything more you would like to contribute that has not been taken into consideration?	What do you feel are important or not so important in relation to the equipment you provide / recommend?	Can you describe how this equipment has affected you and your family? (split statutory / private)
7		Can you discuss how you feel equipment should fit within your role?	Can you describe what is important or not so important in relation to equipment?
8		Can you describe / discuss any factors which impact upon equipment provision?	Do you consider there to be a difference between statutory or privately purchased equipment in terms of the aesthetics, functionality / utility, cost or its impact? Do the same apply?
9		Can you describe the future of OT and equipment?	Do you have any comments relating to the OT input you received?
10		Is there anything more you would like to contribute that has not been taken into consideration?	What are your thoughts on the future of OT equipment provision?
11			Is there anything more you would like to contribute that has not been taken into consideration?

Table 3.15: participant interview schedules

 $<sup>^1\,</sup>$  The abbreviation 'OT' is used here for the sake of convenience, during the interview the full name was used.

The participants took part in a single in-depth interview at a place of their choice and time convenient to them. The clinical leaders and occupational therapists all chose their place of work and the service users their homes. As several visits took place in participants' homes, as outlined in Section 3.3.3 above a member of staff was alerted to the time, place and expected duration of the interview. Once completed, the relevant staff member was contacted to advise them of the end of the interview.

An advantage to interviewing the two support group participants provided me with the opportunity to pilot the service user interview schedule. The need to create a fourth or adapt the existing schedule was considered unnecessary as the essence and purpose of the interview was consistent with the experiences of the prospective NHS service users.

Prior to commencing the two pilot interviews the participants were advised of the interview schedule, and how, due to the nature of a semi-structured interview it may deviate from this dependent upon their responses and the need for clarification or elaboration on the topics arising. After completing the interviews, the structure remained unchanged, however, I included a short introduction which focussed the interview more directly on occupational therapy and equipment. This was read out to the remaining participants at the start of their interviews.

The duration of the interviews varied between 25 minutes and 1 hour and 45 minutes. The interviews were recorded using two handheld digital recording devices. The use of two recorders prevented the loss of data should one of the devices fail during the interview itself and/or be lost whilst transferring the data to secure storage such as a password-protected computer and USB. With the permission of the participants recording commenced once the introductions and consent form was complete.

Except for one participant (sub-group three), none showed signs of distress during their interviews. In relation to the participant who became tearful, immediate enquiries were made about their well-being upon which they clearly indicated they were 'fine' and appeared to quickly compose themselves. The participant was offered the opportunity to pause or stop the interview, but they chose to continue. Throughout the remainder of the interview the participant was observed closely for any further signs of distress or heightened emotion. At the end of the interview the participant was asked again if they were okay, whereby, they apologised for becoming emotional. The participant was immediately advised and reassured that they had nothing to apologise for. In response,

the participant commented on how the question involved was "obviously a good one as it had hit the mark". The participant repeatedly reassured the researcher they were indeed fine and no further follow up was required. Post-interview participant information was offered and declined. This approach reflected the NHS REC application which outlines how any arising 'risks' would be addressed.

During the process of developing the interview questions and process I reflected on the potential 'power' relationship between myself and the participants. For example, it was likely I had worked directly with or alongside a number of the clinical leaders and occupational therapists, or that we were known indirectly. Though it was unlikely I would have had recent, if any, contact with the service users the concept of 'power' remained relevant. I was particularly mindful of whether the participants would be reluctant to fully engage with a past 'colleague' or someone others may view as too removed from clinical practice or within a position of perceived authority. I was hopeful my experience of conducting patient focussed assessments and interventions, other clinically based interviews and teaching would provide me with some of the skills to counter this should the occasion arise. Following the interviews and analysis process (provided in Sections 3.3.8 and 3.3.9) I am confident this was not an issue and my concerns unfounded. During the participant interviews, as with any form of interview or discussion and as is expected with qualitative interviewing, I remained conscious of the importance of accepting and thereby using the participants as the expert of the phenomena rather than myself (Smith et al 2009).

# 3.3.7 Reflexivity

As qualitative research has grown, so has the increased awareness of the need to demonstrate trustworthiness, and as such researchers have sought to achieve this in an acceptable and effective manner (Finlay and Gough 2003). Reflexivity captures the subjective nature of qualitative research enabling its rich source of data to inform the analysis and findings whilst also providing information related to the processes and decisions made throughout the research journey (Finlay and Gough 2003). It provides details of the relationship between the researcher, their assumptions, the topic and the participants (Finlay and Gough 2003). In essence, reflexivity can be described as "where researchers turn a critical gaze toward themselves" (Finlay 2003, p3).

A reflexive journal such as those described by Finlay and Gough (2003), Appleton (2009) and Finlay (2011) captured my thoughts and any decisions made during this research project and subsequent writing of the thesis. It includes field notes taken

immediately after participant interviews and any thoughts which arose during transcription. As an occupational therapist who is used to reflexive practice a range of the types of reflexivity described by Lynch (2000) were used; albeit subconsciously. Accordingly, rather than adopting a singular approach, the reflexive cycle has been approached, which based on the background of the research and researcher, encompasses elements of several of the types of reflexivity Lynch (2002) refers to. This is particularly relevant when framed alongside Lynch's (2000) hermeneutic reflexivity; the form of reflexivity also recommended by Finlay (2011). As a novice researcher, being mindful of becoming overly subjective when acknowledging their subjectivity was important so as not to shift the focus of the research away from the phenomena under study (Finlay 2011).

In addition to this, and the concept of bracketing discussed earlier in Section 3.2.3, the use of a reflexive journal offered a forum for noting practical thoughts and ideas. For example, recording the order of the interviews and later plotting and bulleting the specific order of the three analysis processes. Alongside this, formal and informal supervision with the research team often provided clarity to these thoughts and ideas.

The knowledge that some of the therapists contacted by the researcher may have been known by them (the researcher either directly or indirectly) was a consideration when developing the recruitment strategy. Preventing feelings of power and coercion is an important consideration when developing a research strategy (Clarke et al 2015b). As such, the objective list of occupational therapists obtained from the gatekeeper (Section 3.3.3.1), all of whom were contacted, was considered an appropriate method of reducing the potential for inferred bias. Contact using a generic non-face-to-face invite was intended to prevent individuals feeling compelled to participate. Equally, consideration was given to the service users' perceptions of power with particular regard to their knowledge that the interviewer was an occupational therapist. Being open about the professional background of the researcher was important as a method to convey their understanding of the phenomena and illicit trust between the researcher and the participants. To counter potential bias and perceptions of power, participants selected a date, time and interview venue of their choice; an action designed to place them in a position of control as recommended by Finlay 2003. Equally, during the interviews I remained mindful of participants who may have felt obliged to open up more than they would prefer to due to some perceived sense of power they believed I may have held. As Gough (2003a; 2003b) and Finlay (2011) discuss, this ethical dilemma is both common and challenging to address.

As all of the participants were initially approached either electronically [occupational therapists via email] or face to face by others [service users via the support group leader or occupational therapists not related to the research], the participants were able to make an informed choice about whether to participate without feelings of researcher influence or a sense of obligation. As a guide to ensuring prospective feelings of power and the overall interests of the participants were respected I was mindful of and translated my knowledge and understanding of research and professional ethics into and throughout my research practice (Health and Care Professions Council, HCPC 2016a, COT 2015b, WFOT 2016).

The reflexive journal and field notes enabled the researcher to reflect on the potential influence these issues may have had. With regard to sub-group one (Section 3.3.3.1), the lack of response by eight of the original prospective participants (senior management) was disappointing. Their views and experiences may have provided an alternative perspective to occupational therapy practice and ADL equipment which in turn may have offered an opportunity to observe convergence and divergence within their sub-group and across the three sub-groups as a whole.

# 3.3.8 Explaining the transcription process

The two support group interviews were transcribed first (which later formed part of subgroup three), followed by the clinical leaders (sub-group one), occupational therapists (sub-group two) and lastly the NHS service user sub-group (three).

All the interviews were transcribed verbatim, with most of the affirmative utterances and grammatical confusions included (Finlay 2011). This included instances of pauses/hesitations and laughter, false starts, unfinished sentences and 'erms'. These were included initially, as, though they may have affected the flow of dialogue, there was equal concern how their exclusion may at times impact the meaning of the surrounding discourse. Equally however, reflecting the premise of IPA which is based on analysing content rather than conversation, some intonations and non-verbal and verbal utterances were omitted (Brinkmann and Kvale 2015, Finlay 2011, Smith et al 2009). Examples of the omitted utterances are; the sound 'tch' made by several of the participants, unintentional stuttering and filled pauses such as 'err', 'uh' and 'um'. Likewise, after the analysis process some repeated words and sections of text were later omitted from the thesis itself as they were considered to detract the reader from the point/s being made, the larger sections are symbolised by '[...]'. This practise is

apparent in many IPA texts and papers, examples which include Smith et al (2009) and Finlay (2011) who explicitly refers to this process.

Transcribing the interviews personally provided the opportunity to revisit them in full and prompted the documentation of non-verbal cues and nuances observed during the interviews within the reflexive journal; connections with field notes were also reestablished and could be aligned to the transcriptions. Additionally, the process of transcribing the interviews personally afforded the opportunity to reflect on the interview style and commence the analysis process, albeit informally at this stage (Brinkmann and Kvale 2015, Seidman 2019). Debate surrounding the transcription of interviews by the researcher exists within the literature. Some suggest how the process of transcription by the researcher enhances the analysis process whereas others argue against this (Smith et al 2009, Brinkmann and Kvale 2015).

#### 3.3.9 Explaining the data analysis process

The data analysis process for all four sub-groups followed the premise of Smith et al's (2009) six step approach to IPA. There are, however, slight variations which are explained accordingly as they arose. The six given steps are:

Step 1: reading and rereading

Step 2: initial noting

Step 3: developing emerging themes

Step 4: searching for connections across emergent themes

Step 5: moving to the next case

Step 6: looking for patterns across the cases

(Smith et al 2009, p82-101)

Within step two, Smith et al (2009) breaks down the commentary into three separate processes, these are descriptive, linguistic and conceptual comments. Descriptive commentary requires the analyst to identify key words or phrases from the transcript which are perceived as important to the participant and what base level meaning may be attached to them. Language, non-verbal utterances and pauses are the focus of linguistic commentary. Whereas conceptual commentary involves the researcher questioning the data and a deeper level of data interpretation. During step 4, Smith et al (2009) offers six alternate ways to assist the analyst to recognise patterns across sub-themes and thereby develop super-ordinate themes. These are abstraction, subsumption, polarization, contextualization, numeration and function (Smith et al 2009). Abstraction and subsumption respectively involve the identification of similar

patterns of data across sub-themes which when brought together form a super-ordinate theme, or where the developing theme itself becomes a super-ordinate theme in its own right. In contrast, polarization involves examining the differences which may offer alternative insight and as such assist with the organisation of the sub-themes and super-ordinate themes from an alternative perspective. Contextualization seeks out and aligns similar events from within and across the transcript of which the connections go on to form and develop sub-themes. Whereas numeration is interested in the frequency by which theme content is repeated and function explores how the content of the theme positions itself either from a negative or positive perspective. Whilst some may consider the use of a process somewhat 'prescriptive', Smith et al (2009) described their analysis process as particularly useful for those undertaking IPA for the first time. As a novice IPA researcher, an additional benefit of following a defined process provided me with the opportunity to observe, reflect upon and then fully demonstrate the process I adopted.

Step one of the process involved repeatedly reading the interview transcript and noting any important or noteworthy areas of interest. Whilst Smith et al (2009) suggests recording these notes separately to the interview transcript, to act as an aid memoire I chose to write any comments on a document containing a copy of the transcript with a single column to one side [right] for any notes made. Step two of the process given by Smith et al (2009) requires the use of a document with three columns, the central one containing the interview transcript, the outer one for notes and the inner one for subthemes which are developed as part of step three. However, when purposefully moving onto step two I found the notes made as part of step one also included comments akin to the process of step two. As this had been unintentionally repeated with both support group members transcripts. I chose to continue using the one document rather than attempting to then separate out the notes and comments. When commencing the clinical leader data analysis process, despite effort, I found I was unable to follow the guidelines explicitly and separate the elements of the two note taking steps. As such I found myself reading, re-reading and completing notes within the same cycle. This process was adopted for each of the three sub-groups. When starting step three of the analysis process recording the sub-themes on the same document was challenging due to the small margins. For continuity I chose to maintain the same format for the clinical leader group but then adapted it to the three-column document for the occupational therapist and service user groups to suit my data and developing analysis style.

## 3.3.9.1 Clinical leader group

Further to the process outlined above, each transcript was checked three times for grammatical and pronunciation errors before commencing with the data analysis process. The noting in the right-hand margin (Step 1) included descriptive comments which highlighted points of interest at a basic level, examples included certain events or phrases used by the participant which appeared important to them. Linguistic comments paid attention to the use of the participant's language including the strength of words or phrases which may also have been repeated close to one another or throughout the interview. Other examples were the use of metaphors, laughter or pauses. The conceptual element involved the process of questioning the transcript, for example asking yourself why the participant said or did something, the potential consequences of this and what this may mean to them. Smith et al (2009) describes this concept as the start of the interrogative or interpretative stage of the whole process.

Smith et al (2009) also refers to the concept of deconstruction or de-contextualization which requires the analyst to read the sentences within a paragraph in backward order. Personally, I found this method unhelpful and therefore did not apply it to my data analysis. I did however find myself engaging collectively in all three commentary elements at the same time. Once satisfied, I focussed attention on the comments I had made and began to consider these in terms of potential themes (Step 3) ensuring to make note of the words or phrases which arose in the inner column (as suggested by Smith et al 2009). The developing themes were then mapped (Step 4) to produce tables of themes and super-ordinate themes for each participant. Within IPA a theme constitutes a cluster of similar words or phrases which represents a topic or collection of ideas. A super-ordinate theme is a collection of sub-themes which is named in its own right. Patterns were sought based on Smith et al's (2009) principles of abstraction and subsumption. This involved collating and arranging similar clusters of the subthemes which arose during Step 3. Once arranged, these clusters formed the superordinate themes and were named/renamed accordingly. Consideration to the concepts of polarization, contextualisation and function to enhance rather than replace the abstraction and subsumption was given. Whereas the concept of numeration was not deemed as appropriate and thereby not included. A table representing the individual participant's super-ordinate themes and sub-themes was created based on the version provided by Smith et al (2009). Step 1 to 4 was repeated for each participant (Step 5). Once Step 5 was complete, the individual tables of sub-themes and super-ordinate themes were cross-referenced to search for mutual patterns (Step 6) which, following a

process of 'reconfiguring and relabelling' (Smith et al 2009 p101) resulted in the development of a master table of group themes.

At this point of the analysis process a total of 17 sub-themes and four super-ordinate themes were identified. However, when revisiting these and the transcript/comments documents in preparation for writing Chapter 4 – the clinical leader findings – a particular concern arose. More specifically, the relationship between the experiences of the participants appeared too dispersed or fragmented. As such, I believed the data analysis process and generation of many sub-themes had resulted in a sizeable divide or disconnect between the participants' words and their meaning. When revisiting the transcripts and highlighting the excerpts included in the master table of themes, many were found to be within close proximity. During the analysis process these clusters of excerpts had been split to form sub-themes within their own right. However, this division resulted in several sub-themes becoming less powerful than when positioned back into the wider context of their surrounding sections of transcript. As suggested by Ayres et al (2003), the process of data analysis resulted in the loss of "contextual richness" (p871) during the process of extracting meaningful excerpts.

This understanding resulted in a secondary analysis involving an additional crossreferencing process which began with a return to exploring and clarifying the case-level developing themes (Step 4 and 5) and then re-searching for patterns across the group (Step 6); this was completed alongside the transcripts to ensure the themes remained relevant to, and suggestive of, the experiences of the participants. This process enabled the identification of the key theme within sections of the transcript and to select the most appropriate supporting excerpt/s. Following this inductive process, I was satisfied the themes and super-ordinate themes retained a greater sense of the participants' description of their experiences whilst enabling lower-level redundant themes to be absorbed or discarded. This process highlighted the complexity of the connections between the patient, their families, the role of the occupational therapist and equipment. The intricate interweaving role of the occupational therapist and the skills they use to guide their reasoning, choices and approach to the patients and the issues surrounding equipment is multifaceted. This process resulted in the redevelopment of three super-ordinate themes and nine sub-themes. However, throughout the drafting and writing process, additional analysis took place which gave rise to further shift and development of the super-ordinate themes and sub-themes. As a result, these were refined further and are illustrated below in Table 3.2 as the final three super-ordinate themes and seven sub-themes.

Super- ordinate theme	Themes	Alex	Charlie	Danny	Eddie	Frankie	Harry	Jamie	Lee	Nicky	Present
A Question of Identity	Loss and gain: occupational therapists views	Yes	Yes	Yes	Yes		Yes	Yes	Yes		7
	Professional identity and values	Yes			Yes			Yes		Yes	4
	Restoration versus equipment		Yes	Yes	Yes		Yes	Yes	Yes	Yes	7
The practicalities	Challenges to sourcing equipment	Yes			Yes	Yes		Yes	Yes		5
	Collector's items: funding and resources		Yes	Yes	Yes	Yes	Yes		Yes		6
Moving into the future	Feeling positive	Yes			Yes			Yes	Yes		4
	Feeling threatened					Yes	Yes			Yes	3

Table 3.16: Final set of recurrent super-ordinate themes and themes – clinical leaders

The final column represents which participants were included in the theme/s rather than the number of times they appeared.

A two-page example copy of a transcript, commentary and sub-themes is included in Appendices 6 (step 1, 2 and 3). A single page copy of a document representing the grouped (Step 6) super-ordinate themes and sub-themes is provided in Appendices 7.

# 3.3.9.2 Occupational therapists

Based on the experience of analysing the clinical leader sub-group data, as outlined in Sections 3.3.8 and 3.3.9, the six-step process outlined by Smith et al (2009) was adapted to suit the researcher's data and developing analysis style. Adapting the analysis process is actively encouraged by Smith et al (2009). As such, the interviews were transcribed verbatim onto a three columned document which allowed for hand-written comments to be added to the left and right with the transcript positioned centrally.

Steps 1 through to and including Step 3 were repeated except for the individual table of super-ordinate themes and sub-themes. As an alternative, key words were highlighted on the interview transcripts which then enabled these to be considered as individual points of interest whilst maintaining their relationship to the participants experience and context. Step 4 continued to follow Smith et al's (2009) guidance, however rather than splitting out the key words, associated bunches within selected excerpts were copied onto a new document. These were then arranged into themed clusters within a caseby-case set of super-ordinate themes. Key words were highlighted using an alternative coloured font (see Appendices 7 for an example). Step 1 to 4 was repeated for each occupational therapy participant (Step 5). The case-by-case developing super-ordinate themes and sub-themes (with excerpts) were then cross-referenced alongside the original transcripts which resulted in a group extract master document (Step 6). This process resulted in a total of four super-ordinate themes and 24 sub-themes. These were further refined and developed through the process of "reconfiguring and relabelling" (Smith et al 2009, p101) which involved increasing or decreasing the size of the excerpts to best reflect the key points. Excerpts considered redundant or surplus were omitted. As previously highlighted in Section 3.3.9.1, additional analysis occurred during the writing process of the occupational therapists' findings chapter (Chapter 4). This resulted in amendments to the master table of group themes, the final version is provided below (Table 3.3).

Super-ordinate theme	Themes	Bobby	Glen	Jo	Kit	Kris	Mel	Pat	Ricky	Sam	Vic	Times present
Restoring or compensating	Establishing/re- establishing identity	Yes		Yes	Yes		Yes	Yes				5
	equipment user identity	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9
	professional identities				Yes	Yes	Yes		Yes	Yes		5
	outlining the benefits	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
	restoration versus equipment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
The practicalities	challenges to sourcing equipment	Yes	Yes	Yes	Yes	Yes	Yes		Yes	Yes		8
	funding and resources	Yes	Yes		Yes	Yes	Yes	Yes		Yes	Yes	8
	collectors' items	Yes			Yes	Yes	Yes	Yes	Yes	Yes		7
	being safe			Yes		Yes	Yes		Yes	Yes		5
Moving into the	changing landscapes	Yes	Yes	Yes	Yes	Yes	Yes			Yes	Yes	8
future	feeling threatened	Yes	Yes					Yes			Yes	4

**Table 3.17**: Final set of recurrent super-ordinate themes and themes – occupational therapists

#### 3.3.9.3 Service users

There were no changes or further amendments to the six step analysis process adopted and described in the previous section (3.3.9.2) during the data analysis process for the service user sub-group. Initially, a total of 4 super-ordinate themes and 27 sub-themes were identified. As with the previous sub-groups (clinical leaders and occupational therapists), due to the ongoing iterative process of data analysis these were reconfigured and amended to a total of three super-ordinate themes and six subthemes which are represented in Table 3.4.

During the transcription and analysis process of this sub-group, and the subsequent writing of Chapter 6, I reflected on the inclusion of one participant's comments relating to relatives rather than of themselves directly. As Section 6.3.1.2 highlights Mattie referred to both her mother and mother-in-law during her interview. The decision to include the excerpts in the analysis was based on my perception and interpretation that to Mattie these were memories of experiences which clearly still mattered to her. She was reflecting on others experiences and recognising the difference equipment could have made to the lives of others close to her. The importance of the experience clearly remained relevant as Mattie was recalling events which took place nearly two decades before the interview. As such, it felt appropriate to include them in the analysis.

Super-ordinate theme	Themes	Andy	Billy	Denny	Fran	Mattie	Robin	Tony	Times Present
Loss and Grief	Perceptions of self and others		Yes	Yes	Yes	Yes	Yes		5
	Occupational impact		Yes	Yes	Yes	Yes	Yes		5
Assistive equipment: is	Highlighting the benefits and pointing out the limitations	Yes	Yes	Yes	Yes	Yes	Yes	Yes	7
it?	Accepting and declining	Yes	Yes			Yes	Yes	Yes	5
Making things better	To have or not to have						Yes		1
	Action rather than								

Yes

2

Table 3.18: Final set of super-ordinate themes and themes – service users

reaction

Yes

# 3.4 Summary

Chapters 1, 2 and 3, informed the direction of the current research project. Furthermore, there is a comprehensive overview of the philosophical underpinnings for the research, its design and process.

A clear rationale for the choice and utilisation of the methodology and methods used to explore, understand, and interpret the collected data was provided. The researcher's use of and need for reflexivity has also been introduced. Overall, the selection of IPA was particularly appropriate for this research project because it was interested in exploring the participants' experiences of an event and the significance they placed on it.

The next chapter (4) presents an interpretive analysis of the clinical leaders' experiences of occupational therapy and the provision of equipment for activities of daily living. It begins with a brief summary of the participant's demographics, for example their areas of clinical practice and experience. The developing themes are then explored in detail using transcript excerpts to support the findings.

# Chapter 4: Findings – Clinical Leaders

The previous chapter (3) provided detail surrounding the methodological choices made in relation to the direction of this research project. This and the following two chapters present the findings of the three participant sub-groups: clinical leaders, occupational therapists and service users respectively. Chapter 4 begins with a précis of the participants' backgrounds within this sub-group. My observations and perceptions of the interviews and their engagement within the process is included. Excerpts selected from the interview transcripts are used to support the discussions which arose during the analysis process, these are presented as super-ordinate themes and sub-themes. Each super-ordinate theme begins with an outline of my interpretation of the shared experiences of the participants before presenting each sub-theme in full. Then follows a short concluding summary of my overall interpretation of the findings for this subgroup.

As discussed in Section 3.3.5, all of the participants in this sub-group were assigned a gender-neutral pseudonym to help maintain their anonymity. Furthermore, participants are referred to as 's/he' where the narrative flow was affected using the pseudonym or term 'therapist'. In addition, where participant information is provided this is summarised as a collective rather than singularly. This has been especially pertinent in a smaller organisation such as the one participating in this research project.

# 4.1 Participants

Overall, nine clinical leaders consented to be interviewed. The length of interviews ranged between 38 minutes and 1 hour 46 minutes with the majority taking approximately 60 minutes. The participants described themselves as working at a senior level either as clinical or therapy team leaders or managers responsible for the day-to-day management of a service and its staff. Their past and present history of clinical experience includes working with all age groups across inpatient and community contexts. An expectation of the clinical leader role is to manage others with direct service user contact whilst also maintaining a clinical caseload of their own. The participants in this sub-group and those they managed all assess for and provide equipment for activities of daily living (ADL) within the home environment. Typically, service users' had one or more chronic long-term condition and/ or required an acute medical or surgical intervention which resulted in moderate to complex occupational performance needs.

## 4.2 Interviews

Although subtleties in demeanour were noted, all nine participants engaged well with the interview. For example, Charlie expressed feelings of nervousness prior to starting their interview whilst Frankie appeared nervous compared to the other seven participants (Alex, Danny, Eddie, Harry, Jamie, Lee and Nicky) who all presented as relaxed and unconcerned throughout. During the interviews and the transcription process my overall impression was one of honesty, though some of the participants were clearly more candid (Alex, Danny, Jamie and Nicky) and less circumspect than others. For example, Charlie and Lee appeared more cautious giving the impression that care was being taken to select language which whilst being honest was also measured. Eddie, Jamie, Lee and Nicky were composed and less reticent compared to Charlie, Frankie, Harry and Eddie who displayed some hesitation when exploring or describing negative topics. As such the responses they provided and perceived as negative by the researcher were more considered. Equally, Charlie came across as apologetic, at times seeking reassurance from the interviewer that their responses reflected the questions. Whereas Danny appeared unconcerned about professional etiquette (RCOT 2021a). This form of impression management is not unusual during interviews as participants are often protective of themselves, others and their organisation. Alex, Danny and Jamie were clearly passionate about their roles and service users' needs. This was evident through their words, facial expressions and gesticulations, particularly Danny who frequently banged the table to emphasise their point. All the participants responded with humour, which at times reflected nervousness, a sense of irony or acceptance. Alex commented on the interview as a positive experience as it had caused them to reflect on their service and consider how it could be enhanced to improve the service user's experience. In contrast, when asked if they had anything to add Frankie stated:

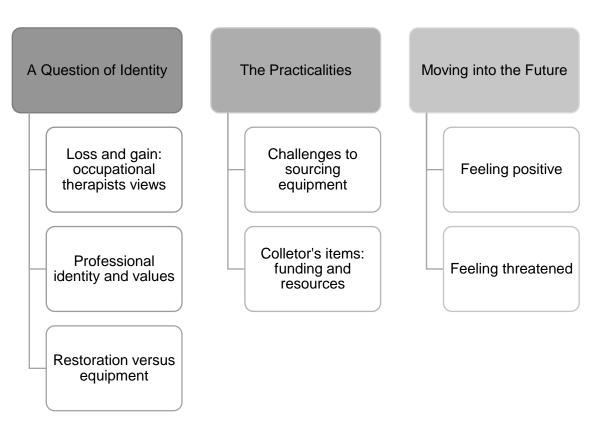
"F: not that I can think of R: okay [both laugh] F: I feel like I've been grilled [laughing] R: oh sorry F: that's okay [still laughing] it's like a job interview [both laugh]".

This may account for the sense of nervousness, hesitancy and considered responses observed during Frankie's interview. Similarly, Harry requested the questions be repeated on three occasions during their interview; they stated, "*my brain my brains gone numb*".

# 4.3 Super-ordinate themes and Sub-themes

Overall, three super-ordinate themes and seven sub-themes arose from the data analysis and throughout the writing process. These are presented in Figure 4.1 below. Each super-ordinate theme is introduced before the presentation of each sub-theme which are supported by transcript extracts. This method of presentation employs the 'case within theme' (p109) approach outlined by Smith et al (2009).

# Figure 4.1: Final set of super-ordinate themes and sub-themes – clinical leaders



# 4.3.1 Super-ordinate Theme: A Question of Identity

The following super-ordinate theme provides insight into clinical leader's perspectives of how the provision of equipment had the power to restore or remove user identity. This was achieved through an exploration of the clinical leader's experiences of equipment provision and their perceived understanding of this on the service user, others and themselves. The sub-themes are presented in the following order: loss and gain: occupational therapists' views, professional identity and values, and restoration versus equipment.

# 4.3.1.1 Loss and gain: occupational therapists' views

When referring to past experiences, Alex provided a profound insight into the benefits of provision. Alex voiced the notion of equipment instilling 'an identity' on the individuals they had worked with and the impact this had on family. With reference to specialist seating, alongside a sense of professional satisfaction, Alex commented on the emotional impact provision had when family suddenly see their loved ones as a being in their own right. This is particularly significant when individuals can engage with their physical and social environment, in some cases for the first time:

"I absolutely love to bring really good specialist seating into the home and get the child sat and see their parents faces because when the child sits you see their size you see their height you see them have some head control they have eye contact the emotional effect of getting a child in a good position as you know like with wheelchairs suddenly the strain of being separated from the parent being not held and having that stability I think when you see that that's a huge relief and it offers parents to actually look at the child and see them for who they are".

This extract highlighted that whilst there may be an underlying sense of loss in terms of the child's ability and capabilities, the equipment provided enabled individuals to gain function and achievement alongside heightened parental emotions. Here the equipment user and parents both acquired their respective identities. Moreover, effective equipment provision enabled the restoration of family characteristics and roles as the individual became less occupationally reliant and dependent on others. Alex inferred this sense of responsibility toward the importance of reinstating family roles by describing equipment provision to enable family to be simply that – family. Alex referred to one experience:

"she [mother] said the first five years of her life she didn't feel a parent she felt like she was a therapist a doctor a health visitor and she missed out on being a parent because she was so focussed on the health and therapy needs and I tried to take that off them and let them just be a parent".

The opportunity to dispose of multiple identities, such as those in the above excerpt, were repeated by several participants. For example, Charlie and Danny highlighted the benefits and impact of regaining independence, including reducing the need for formal and informal carers, the latter of which are invariably family members. Here equipment enabled service users to return to an improved level of independence which had the effect of restoring both theirs and others preferred identities. As such, Charlie viewed

equipment "*as a positive*" element of their role, making a strong connection between the enabling qualities of equipment, the sense of empowerment this invoked and the ensuing natural outcome this had on equipment users "*quality of life*". Whereas Danny viewed equipment as a "*simple option*" which facilitated an individual's return to a level of functional independence through compensatory environmental modification. By providing a few simple pieces of equipment:

# *"I'm out of there they don't need me anymore they've got their life back on track"* (Danny).

Here Danny recognised equipment provision as a specific singular solution which was timely, effective and the least clinically intrusive, particularly when compared to alternative sometimes extensive environmental adaptations. In essence the simplicity of equipment and its provision ensured service users were able to regain their sense of self and return more quickly to their previous lives and lifestyles and thereby less reliant on others who were able to return to their prior roles. Whilst Danny's view of equipment and its association with identity was both positive and clear, in contrast Jamie's was less so. For example:

# "in this setting it's very much a means to facilitate discharge it's [...] that's what it's about and we're it's very focussed on what's essential for discharge".

Both Danny and Jamie referred to equipment as a compensatory approach. However, although Jamie emphasised the benefits of equipment to facilitate discharge this highlighted the constraints of the occupational therapist's role. The implication here is that in the circumstances of hospital discharge equipment is a purely pragmatic solution which does not consider the service user and as such is a means to a process driven end. Although the link between equipment and identity was evident through both Alex and Danny's words, it could be argued the more pragmatic approach still provided a parallel yet objective outcome in terms of restoring identity. With the latter, the concept is less tangible and transparent and as such was viewed as purely functional rather than from an equally important emotive perspective.

In contrast to the perception of equipment establishing or restoring identity, several participants recognised how provision may in fact endow individuals with an unwelcome identity and what this may represent. Rather than offering the potential for 'gain', in reality there was a sense of loss. For example, Alex acknowledged the

challenge of coming to terms with the need for what was essentially unwanted equipment in the home, particularly when there was hope "*that with all the therapy and input things will improve*". As such, both Alex and Danny stressed the importance of ensuring positive first impressions as this would affect whether equipment was accepted or declined. For some service users, the initial response and reaction to equipment was strong:

"the big thing I have when I first bring the piece of equipment into the room or into the house is like a gasp of oh my God what's that because it is often looks big it's it's alien" (Alex).

Alex reinforced the importance of outlining the benefits of any proposed equipment so individuals could see beyond the aesthetics and so "*are often calmer about it they don't seem as freaked out*". Harry compared people's perception of equipment aesthetics to "*Marmite*" implying a simple more pragmatic sense of acceptance or decline rather than one related to any sense of identity. Similarly, Eddie speculated about how people were or were not always affected by how equipment looked "*it works and it meets my needs*". Whereas Lee empathised with service users who struggled with "*the concept of a piece of equipment*" and what it represented. Danny recognised the importance of occupational therapists being equipped with sufficient knowledge of the wider options available and as such directed service users to alternative high street or online sources. This approach may assist some service users who struggle to accept equipment and changes to their lifestyle by enabling them to purchase items they feel more comfortable with aesthetically and therefore better reflect their preferred or desired identity.

Eddie and Lee touched on the need to spend time with service users and attempt to understand their feelings about equipment, particularly where there was a reluctance to accept it. Eddie and Lee referred to the emotional impact service users experienced when faced with the prospect of needing equipment in terms of how they identified with it or perceive how it identified them. For example, in terms of identifying with equipment:

"I suppose it's going that bit extra isn't it to try and work with people people have funny ideas as well about equipment and it's trying to work with them and get to the bottom of them so ... sometimes people don't want things cause of it was what my mum had and she was dying or all those thoughts that you might think are quite irrational but once you dig a bit deeper there's a lot of family sort of history and things they associate with that rather than just sort of well this is what you need it's trying to talk that through with people so there's I guess equipment is quite emotional for so for people" (Eddie).

This returns to the earlier discussion about the subjective and objective nature of equipment provision and the need to be mindful of its emotional impact. In this example, Eddie had experienced the associations service users have with equipment which affected their willingness to accept it as part of achieving their goals and a return to some form of normality. In some instances, the negative association originates from others, but will influence the service user who then choose to decline the equipment because they are aware of the impact accepting the equipment will have.

Alternatively, for some, in addition to the association's individuals make, there was a view of equipment in terms of health status and how equipment is representative of your identity:

*"it's a very clear symbol that you've got a deteriorating neurological condition"* (Eddie).

"people are more mindful of the visual impact of having equipment in their house and what it symbolises you know as the decline through palliative condition" (Lee).

Similarly, Danny raised the point that service users "feel ashamed because it labels them disabled" whilst Harry recalled service users "who don't want to look old [smiling] can't possibly be seen in a wheelchair". Whereas in contrast, Jamie found it "really interesting how people react to equipment" recalling how some service users "must have the full vast array of everything" whereas for others the concept of equipment was "unbearable". This implied a consciousness of how we perceive our own relationship with equipment and identity but also a view that we are influenced by how we believe others identify with equipment and us.

Eddie highlighted how patients' emotional and psychological well-being can be affected by the limitations of statutory provisions. The consequence of preventing closeness in an important area of life can affect continued personal identity resulting in harm to the immediate or longer-term relationship: "I think some equipment again cause of the constraints ... doesn't fit into family life for example we can't get double beds double profiling bed and people might want to continue to sleep together so you're actually separating partners and ... that's not good".

This reinforced the concept that more than the service user's identity and emotional well-being is impacted by equipment. Standard profiling beds [hospital] provided by statutory services are typically single and due to their size and weight are most frequently situated on the ground floor. Few properties can accommodate a single profile bed next or near to a second single bed. This results in spouses, partners and children being unable to occupy the same space as they would have previously. This therefore affects the service user and those around them.

# 4.3.1.2 Professional identity and values

Whilst the impact of equipment on service users and those who immediately surround them is paramount, the relationship between professional identity and equipment was equally important. For example, though highlighting the positive outcomes of equipment provision, Jamie stoically recalled how "*the role of an OT in an acute setting has changed massively in the past decade*". When comparing the limitations of current clinical practice to those of the past Jamie implied a sense of doing 'what has to be done' rather than 'what could be done':

"we don't really go beyond that to look at things like people's real meaning and purpose and occupations [...] we're just looking at real basic stuff'.

Similarly, Nicky linked the approach of an acute setting and equipment provision to "*a* safe discharge and being able to function in your own home". In essence, to a level which enabled individuals to complete basic personal activities of daily living. In contrast however, from a rehabilitation perspective, occupational therapists:

# "[are] looking at very much the individual their environment and being able to carry out the roles that they've always done" (Nicky).

This implied a clear shift toward a compensatory approach within an acute setting compared to the restorative opportunities afforded to those involved with long term interventions. Underlying this was a correlating change in professional identity from one which enabled occupational therapists to complete a holistic assessment to one which was compensatory in its approach and increasingly discharge led. An additional

implication of this enforced shift in identity, was the effect this had on the personal and professional values of the occupational therapists involved.

A key issue affecting professional identity was raised by several participants, namely in relation to their experience of sourcing non-standard equipment via a weekly convened equipment panel overseen by senior management. Challenges arose as these 'managers' were not necessarily occupational therapists by background and thereby were perceived to lack understanding of the profession, its relationship to, and the purpose of ADL equipment (Alex, Eddie). Participants described the almost constant questioning of their clinical reasoning as having a negative effect on staff "*self-esteem*" (Alex) and confidence (Eddie). Alongside this there was an inferred lack of trust, which had the effect of demoralising the staff involved (Eddie) leaving them feeling "undervalued" (Eddie). Alex's frustration around the matter was clear: "they're questioning what we do and that shouldn't happen". Jamie expressed similar sentiments of frustration with the "palaver" of panel and the feeling of being 'patronised' it evoked: "I've done my assessment I know what the person needs". This sentiment was reiterated by Eddie:

# *"it's quite frustrating because you wouldn't ask for a piece of equipment if somebody didn't need it".*

Alex highlighted how the lack of understanding of the occupational therapist's role correlated with a lack of ability to spend time researching equipment options:

"my managers aren't OTs I don't feel that they understand the role [...] I find that the mangers within the community team where the equipment is ordered and purchased are very adult focused and they don't understand the equipment that I'm asking and why I'm asking for it so I don't think that people take it managers take it as serious the need is as serious and the fact that it's needed for to affect future ... reduce the impact of the disability in the future".

# 4.3.1.3 Restoration versus equipment

In the two previous sub-themes (4.3.1.1 and 4.3.1.2), the benefits of a compensatory approach to equipment provision were introduced. However, whilst some considered this a primary enabling approach others viewed it as a less welcome though financially cost-effective solution where the impact on its users was at most a secondary outcome. As such, the emphasis was purely on low cost and not necessarily cost effectiveness. Whilst it could be argued that the modification of the environment through the medium

of equipment has the potential to impact positively on local resources and timely discharge, particularly during periods of austerity. There was a sense this overrode clinical need and person-centeredness which ultimately challenged the core concept and values of occupational therapy practice. Similarly, to Charlie and Danny, Nicky linked equipment and independence with the potential for reducing the number of carers required which further highlighted the financial benefits to local organisations and service users. Nicky also recognised other benefits this had on service users:

"it's functionality it is about maintaining independence but there is part of me as I'm getting more experienced I start thinking about the cost side of things I'm thinking about the being able to cut down on the carers and that side of things I think and also for the patients as well because I think if we can provide something that they can enables them to function in their own home and reducing the need for a carer it's saving costs for them as well you know and when they don't need it [...] if a patient can do some'at so much for themselves with just that little minimal input I don't want his carers going in and doing everything for them and taking that element of independence and I'm sure the patients feel the same so I think it is more of a functional reasoning why we do it really and you do have the pressures of discharge whether I don't like to say that but that's the way that the hospital setting is as well so it's a case of getting a patient home as soon as as well'.

Here Nicky viewed the provision of equipment as a positive outcome for the service user. To further support this Nicky recognised how experience influenced their rationale for provision. This included how equipment could reduce the financial burden to local services and how timely provision facilitated discharge. Nicky's viewpoint fit with a purely compensatory approach which viewed equipment as the primary occupational therapy intervention. However, Nicky also associated equipment with independence which negated the need for additional support. Both these viewpoints were cognisant with the values and ethos of occupational therapy practice to promote independence and occupational engagement whilst also ensuring interventions were efficient and effective (RCOT 2020a; 2021a). Equally, Nicky's words suggested that in early clinical practice there was less consideration to the financial implications of interventions. Nicky was clear that the purpose of equipment is for independence, but that perhaps early provisions are less considered in relation to the financial implications. Here, Nicky debated the purpose of equipment, whilst illustrating the internal professional conflict surrounding the provision of equipment and the link to personal and professional values. However, consideration should also be given to the impact of increased

equipment provision on the long-term needs of individuals who may become prematurely over reliant on it compared to the costs of providing longer term therapy service input.

Several participants expressed a range of views related to the compensatory use of equipment compared to that of a primary rehabilitative approach. Though not necessarily unexpected, Charlie, Eddie and Harry all implied the balance between equipment provision and rehabilitation varied dependent upon the remit of the service and service user diagnosis and prognosis. On one hand Nicky believed equipment was too readily prescribed as it was "*so easy to compensate as opposed to rehabilitate*". Whereas Eddie recalled their experiences of not providing equipment to prevent 'deskilling' whereas at other times it may well be "*the* […] *main solution*". In contrast Eddie referred to occupational therapists continued "*need to find it and fix it and therefore the only thing you can do is to offer this piece of equipment*". An approach Eddie identified as a medical rather than a social model of disability which they believed remained indicative of current occupational therapy training.

Danny and Nicky highlighted the complex balance of equipment provision dependency and non-dependency on the patients' needs. On one hand, occupational therapists were able to continue to explore restorative options to facilitate functional independence. Conversely however, the act of providing equipment may enable longer term independence or facilitate timely discharge, which in relation to psychological wellbeing improves outcomes in the longer term. However, depending on your clinical stance, the second option can create unnecessary equipment dependency or the opportunity to return home and convalesce in your preferred environment.

The accepted use of equipment as part of rehabilitation programme was voiced by several participants including Charlie, Eddie and Lee. However, they conceded that due to external factors such as time (Charlie) and "*pressure* … *to get through cases*" (Eddie), provision could be less considered and used as a "*quick fix*" approach (Eddie, Lee); an approach, perceived by Eddie as one favoured by management in times of austerity. Nicky's viewpoint was clear:

"as soon as they're medically stable you need to get them out and they [managers] see equipment as just a way of facilitating that safe discharge". While from a management or organisational perspective this may be acceptable practice, for some service users, returning home with a commode could be *"detrimental"* (Nicky) to their recovery, dignity and psychological well-being. Nicky believed that in the future:

"we're gonna see more equipment because the emphasis is on community services now and getting people out of hospital as soon as possible you're seeing less rehab units now [...] you're needing to compensate more which is sad really".

Historically the role of ward based occupational therapists was restorative rehabilitation-based patient interventions with less emphasis on equipment-based approaches (Jamie). Whereas now, to meet current policy and facilitate timely discharge the emphasis is now on a swift response to which Jamie admitted *"I'm not thinking restoration I'm thinking how do we compensate"*. In essence, there has been a fundamental shift in the ethos of hospital care from one of *"convalesce"* (Jamie) to facilitated early discharge. The consequence of this is the increased need for equipment to accommodate the complexities of patients who are *"not as well as they might have been 10 years ago"* (Jamie). Equally, Lee questioned the value of equipment in favour of rehabilitation, particularly, in time limited circumstances:

"actually people are valuing and seeing that actually while rehab is great it sometimes doesn't work and so that you need to do the compensation approaches [...] actually when you're trying to rehabilitate a deterioration a deteriorating patient ... the scope for improvement is limited and actually in the real world ... compensation approaches are often better".

Jamie and Eddie introduced the concept of a cultural shift which accounted for occupational therapists prematurely reaching for equipment. This concept reflected a *"litigious culture"* (Jamie) which encouraged some occupational therapists, particularly those with limited clinical experience, to complete a less functional assessment and reach for equipment rather than acknowledge and accept levels of risk [Eddie]. Jamie linked the issue of risk aversion with current practice, university learning and newly qualified staff in relation to high volumes of equipment provision:

"we're quite risk adverse so a particularly when you're new to the service it's really hard to say well this person's been doing this in this way and just because it's not how we learn how to do it in university if they go upstairs in that way then that's their choice their capacity as adults with regard to this decision and if that's how they chose to do it we need to back away and show respect but some people some particularly newly qualified staff will feel the need to put loads of equipment in because then nothing will go wrong whereas you might say ... you're cluttering up this home with lots of equipment [...] and also not allowing people to recover from their illness and then they don't need the equipment".

Regarding the acceptance of risk, the cultural differences between clinical areas of practice was highlighted by Eddie: "*I guess if you come from a rehab background it's okay to take the risk*". Whereas similarly to Jamie, Lee associated risk with experience:

"I think junior staff want to do good [...] and on the whole they do a good job but there's they can become over reliant on it and I think there's an element as well although of them being very restricted in that no you can't do this and having these kind of fixed rules whereas I think more experienced staff will take more chances will and therefore maybe will take more be a bit more permissive in their risk assessment with patients and listen to the patients a bit more [...] I think there's an element of care of our junior staff trying to eliminate all possible risk and not listening to the person's preferences and desires".

Eddie later raised additional concerns surrounding occupational therapists' approach to assessment, including risk, which whilst raising service user dependency, had clear implications on resources and professional ethics:

"it depends on maybe the experience of the clinician going in [...] to solve this problem let's put this equipment in and it's about risk isn't it as well I think the litigation and equipment is massive so you're taking a risk an it's I guess if you come from a rehab background it's okay to take the risk [...] it's taking that risk with people isn't it ... I've certainly come across it in the past where err ... it's obvious [...] an OTs gone out and they haven't actually physically seen somebody move [...] I've gone in and an they've got tracking hoist put in by a DFG when actually this person they can transfer [both smiling ruefully] [...] it's really hard then if they if they've got some equipment in to then come in and go actually let's try and get you do it yourself so it's a shame really that you're kind of deskilling people ... erm ..... and like I say I presume it's cause they haven't actually seen somebody move they've just come and done a talking sort of assessment that hasn't involved a physical ... assessment [both smiling].

The RCOT (2021a) is clear about the use of professional reasoning to inform future interventions and recommendations. The effective use of clinical reasoning in practice requires a robust and informed assessment. In relation to ADL equipment which implies an ability to move, and function suggests the need for a physical assessment to

identify deficits in occupation and establish ways to accommodate or enhance capability. The provision of equipment without a form of assessment would result in higher levels of dependency. For Eddie, believing equipment had been provided without a functional assessment placed them in a challenging situation from the perspective of professional standards and the detrimental impact such an omission on the longer-term occupational ability of the service users involved. In addition, the increased dependency would impact family, friends and other statutory services. Overall, the capacity of equipment to "*empower*" (Charlie) service users was discussed by the participants. Equally however, there was a call for greater emphasis to be placed on holistic in-depth assessments with less focus and reliance on equipment (Charlie, Eddie).

# 4.3.2 Super-ordinate Theme – The Practicalities

The following super-ordinate theme highlights issues raised by the clinical managers as affecting their ability to source and access equipment whilst exploring the repercussions of over-prescription. The themes are: challenges to sourcing equipment, funding and resources, and collectors' items.

## 4.3.2.1 Challenges to sourcing equipment

Supplementary to the issues related to identity, the participants experienced various challenges in sourcing equipment. One of these related specifically to the 'panel process' which involved staff submitting a written request for specialist equipment items. Whilst acknowledging the high cost of equipment, Alex implied a lack of contextual understanding or empathy by senior management toward the situation and equipment being sourced: *"they've never seen the child they've not been in the house"*. Likewise, Eddie referred to a 'disconnect' between the panel members (senior management) and clinical practice which comprised of clinical leaders and occupational therapists. Eddie intimated how the reality of life from a service user and clinical perspective guides decision making processes and the rationale for provision, which senior managers did not relate to:

"from a clinical role you're very much looking at ... somebody's occupations how to promote their independence [...] I think as a clinician it's very very hard when you're in somebody's home and ... they're really needing a piece of equipment and you know it's gonna be hard to get for them I think that that's quite tricky and I think sometimes [...] the managers don't appreciate sometimes the situation that clinicians will find themselves in". Here, Eddie believed that senior managers failed to identify with service users' and their needs. However, interestingly, as a clinical leader Eddie separated themselves from the management side of their role and aligned themselves as a clinician. This perhaps purposeful disassociation to a management role may reflect Eddie's loyalty toward a preferred clinical identity. Whereas relating to equipment generally, Lee believed:

"there's a desire to make things work that are cheap and to use equipment that are already in in stock because it's more convenient for the budget now it's a bit like I was kind of use the analogy of err you wouldn't ask a surgeon to create to do to do a hip operation without the hip correct hip components but we're being asked to [...] be very creative in our solutions [...] I know I could do a lot better".

The requirement of sourcing inexpensive equipment from stock is not an unrealistic expectation of clinical practice, neither is the need for compromise or creativity in terms of accommodating budgets (COT 2015). Alex highlighted the need to "*compromise*", to prevent the domino effect of equipment provision, particularly where the physical environment was limited. The ability to identify the utility of equipment to service more than one functional activity was essential: "*the family can't live a normal family life because they're tripping over equipment*". As such, though the individual would benefit from a range of equipment items, they simply could not be accommodated in the property.

However, with specific reference to the last few words of Lee's statement above, the degree to which enforced compromise occurred, gave rise to the question of what impact this had on the long-term morale of the staff. Lee clearly recognised how creative panel requests may cause "*raised eyebrows*" and thereby "*cast[s] into doubt*" the reliability of equipment requests. Lee equally highlighted how continued compromise would lead to apathy amongst the therapy staff and a negative cultural shift by management which placed resources constantly above the needs of the service user. Alex referred to a lack of trust by senior management. Though perhaps more powerful when heard, their feelings of anger and frustration clearly remained evident through the written word:

"the problem with the panel at the minute is I see they're taking away our clinical exper our clinical judgement our clinical reason our judge I felt I feel that they're taking away what we do they're questioning what we do and that shouldn't happen". While participants clearly understood the need to manage limited resources, they generally viewed the process of accessing equipment as "*filtering out*" (Eddie) what could and could not be approved. Frankie described clinician's priorities as the service user, and how they [as the clinician] had little or no understanding of the "*financial constraints*" services faced. Frankie implied that junior staff tended to "*aim for the gold standard*" whereas more experienced staff considered broader options, and senior managers were driven financially and asked, "*what do we have in stock what can we make do with*". As a clinical leader, Jamie recognised the reality of limited resources whilst acknowledging that occupational therapists without a leadership or management role would "*think less about it*" and "*become very frustrated that you can't have everything that you want*".

Conversely, despite the negativity surrounding 'panel', it was viewed as a helpful 'backup' in challenging situations where statutory provision was unable to meet service user expectation (Eddie). However, this was an ethical dilemma for Eddie as service users may then have chosen to source unsafe, clinically inappropriate, or unnecessary equipment. Alex, Eddie and Jamie agreed that a 'form' of panel ensured consistency of provision across the Trust which if not in place, would have major implications on resources and parity. Lee also described the creative opportunities and advantages of accessing alternative pots of monies that would be closed if the panel had not been approached and subsequently declined the request.

## 4.3.2.2 Collector's items: funding and resources

Several participants expressed concern with the volume of unused equipment they found when visiting service users at home. Concerns generally centred on the amount of equipment which remained out of circulation and the implication this had on resources which are not finite. Equally, if not more importantly this raised questions surrounding the provision of this equipment in relation to robust assessments [Section 4.3.1.3] and as such whether the equipment was issued according to need. Retrospectively identifying areas of over prescription is restricted as a number of unknown factors may have influenced why the equipment is no longer in use. As a solution, the participants recommended a robust method of review and return to prevent equipment morphing into a piece of 'pot plant furniture' or a method for "*drying your tights*" (Eddie). Harry summed up and proposes:

"it's around encouraging patients to send back what they're not using instead of putting it in the garage for a rainy day [...] they've got all equipment known to man but they only use two bits".

In addition to this, Danny referred to a range of issues related to resources, the benefits of equipment and the clear lack of a persuasive method to evidence good practice and outcomes. They raised the issue of pooling or being more creative with budgets, stating an equipment service was:

"a very expensive service ... because the outlay of x thousand pounds a year on equipment doesn't have an apparent return and I think that something we fail to do well is have sufficient robust outcome measures to actually have evidenced the impact it has we get thank you which say how good it is we get hearsay we get assessments back self-assessment back from how well the service did but to have a robust applicable outcome measure is something I don't think we've got to yet and I think that's a problem because we don't necessarily have the data to go to our managers and say yes you've spent ten thousand pounds on that but actually that meant that you know fifty people who could continue to have a bath and spending four hundred pounds on a bath lift instead of six thousand on a wet room it's all the same pocket it might come out a different pocket here but it's all the same big ball".

Danny was openly passionate about the use of outcome measures to evidence the impact of equipment from the perspective of the equipment user. They reinforced the need to demonstrate outcomes which related to the actual use of the equipment as opposed to that of other performance indicators which highlighted the number of service users seen within a predetermined timeframe:

"we often go out and see the difference it makes in a person's life and it's getting that evidence to be in front of both our line managers but also the commissioners to show that we are actually having an impact on peoples life and improving quality of life forget about state of housing forget about finding jobs and things but this person can now get into the kitchen and make themselves a meal ... or can get out of bed can get back into bed in the middle of the night without having to wake their husband up you it's stupid things to somebody but that's important that's to that person key and I can do it now is just a buzz [laughing]".

Earlier in their interview Danny in general queried how feelings, emotions and impact could be measured, which they implied are not easily quantifiable. Danny referred to a narrative of evidence rather than one explored by numbers which highlighted an ingrained unconscious use of quantitative rather than a qualitative approach when demonstrating impact to budget holders and commissioners:

"how do you put a number on that sort of thing but equally how do you quantify that when you're trying to sell a story to somebody about how what a big impact we can have on somebody's life".

Danny believed that equipment:

"could be an incredibly effective tool in helping people to maintain their ability at a snip of the cost of care".

but opined:

# "if we can't evidence the change in that person's ability [...] managers and commissioners will just see it as a cost they won't see it as a benefit".

Whilst this section has focussed on issues surrounding funding, resources and evidencing the benefits and impact of equipment through outcomes, underlying this is the unseen implications this has to occupational therapists and their practice. As many occupational therapists and others will attest to, the relationship between occupational therapy and equipment is synonymous. It could therefore be argued how equipment is integral to the identity of occupational therapy practice. As such, underlying the tone of the participants is the need to ensure equipment is issued appropriately and its impact measured effectively. Equipment, which is superfluous, particularly in large volumes, is considered an ineffective use of resources and by association those who provided it. This could result in occupational therapy practice in some areas becoming redundant.

Equally, the literature review previously highlighted concerns around the non-use of equipment provided by occupational therapists and others (Sections 2.7 and 2.8). This issue was raised by several of the participants interviewed during this main research project who provided their understanding of the phenomena. For Eddie, there was a need to acknowledge a person's goals and at the same time, encourage and engage service users to make their own choices. This would help patients to invest in their own solutions to the difficulties they face. This reinforced recommendations to complete holistic assessments rather than just providing equipment (Charlie and Eddie), which Eddie contended was perhaps not required in the first place. Danny introduced the notion of 'a rut of provision':

"this is what we do because that's what we do this is what we do because this is what's required".

This further reinforced the notion of therapists following a medical or reductionist model, either because this is what as occupational therapists we have always done or are now not able to do anything due to a shift in organisationally led cultural practice. The non-use of equipment was aligned to the pressures experienced by occupational therapists working in acute services. Charlie indicated constrained time frames are responsible for the perceived need to provide equipment as part of a compensatory 'quick fix approach' to facilitate timely discharge. However, whilst Danny recognised the pressure staff face and a lack of "*time to think*", they referred to how "*bad habits have been built up*". This implied how the pressure of time constraints impact the opportunity and willingness of therapists to consider other options and challenge the result of this shift on current practice. This concept was reinforced by Charlie, Danny and Harry who questioned the dependability of occupational therapy assessment and expressed their feelings of despair (Charlie and Harry) when finding equipment being misused by service users:

"your heart sinks when you go in to somewhere and you see you know there's the there's the kitchen trolley with a pot plant on it and things like that" (Charlie).

Similarly, Eddie referred to service users who had:

"got trolleys that they've got the tights hanging on and you know a lot of equipment that's not being used".

The inconsistency regarding equipment training as a cause for a reduction in equipment non-use, was highlighted by Eddie. They advocated the need for a coordinated core approach which facilitates open discussion and shared experiences with the opportunity to problem solve rather than a mechanical demonstration of how to fit equipment.

In contrast, Lee linked the 'non-return' of equipment to individuals who take statutory services, such as the NHS, for granted, thus placing no value on the equipment itself or its origins. Lee recalled:

"opening somebody's garage [...] it was literally like an Aladdin's cave or a small equipment store".

They reconciled this to some extent by recognising how service users' needs altered either through cycles of improvement or decline before then highlighting how equipment was not returned:

"people change don't they people start of well maybe needing some aids and then maybe get poorly need a review of that provision then go through a period of rehab and are provided with more aids and get better and that kind of progression and change so their equipment requirements change and then there's a failure of ... either the relatives or staff going in to inform the equipment service that this stuff is surplus to requirements" (Lee).

Lee discussed the need for occupational therapists to identify what service users' value most about equipment. This in turn would result in equipment being better cared for and returned when it is no longer required. Improving returns processes and encouraging staff to act when they come across equipment which is not in use. However, Lee then confessed to how removing equipment is as equally difficult:

"you get the patient who's got three trolleys and they've been provided with stuff and actually we've no record of it cause they've had it for so long but stuff's really used and was well valued you know you do go into places and they've got everything under the sun and it's all half the furniture actually [laughing] is trolleys and over bed tables isn't it ... it's whether we then and you can't really drag it all back can you so I think there's an element of turning a blind eye in some situations as well rightly or wrongly I probably shouldn't be saying that as manager should I but ...in in certain situations don't kind of you know the persons out there functioning well fine yeah".

Here, although Lee's role was as a clinical leader, s/he openly admitted to the difficulty of removing superfluous or unused equipment. As previously noted in Section 4.3.2.1, whilst the clinical leaders interviewed for this main research project were fully aware of their roles and responsibilities they often identified more closely to the role of an occupational therapist when discussing the reality of practicing in service users' homes.

Charlie, Danny and Eddie conceded how some equipment no longer in use due to functional change but owing to a "*little loophole*" (Charlie) or the lack of a missing "*mechanism*" (Eddie) to review equipment use in the long term, it remained in situ rather than being returned. According to Frankie, a consequence of over prescription resulted in the reduction of equipment items provided through statutory services, such

as smaller inexpensive items. If equipment continued not to be used and was hoarded rather than returned, the potential removal of further items which could be provided was anticipated. Counter to the reduction of the small items available, the limited scope of statutory equipment focussing on elements of "*personal care*" and "*basic occupations*" (Eddie) had resulted in an increased volume of un-used privately purchased small one-handed gadgets. Alex, Danny and Eddie all intimated the need to maintain a good working knowledge of smaller equipment items, with access to an assessment kit, to prevent unnecessary and consequently abandoned purchases.

## 4.3.3 Super-ordinate Theme – Moving into the future

This final super-ordinate theme was the clinical leaders' view of advancements in technology and concerns for occupational therapy practice of the future. The two themes are: feeling positive and feeling threatened

## 4.3.3.1 Feeling positive

Several of the participants were positive about the future of occupational therapy and were keen for service users to continue to be advised about equipment and their choices. Several participants foresaw equipment continuing to be part of the occupational therapy role whether it is provided or simply prescribed. Alex expanded on this by discussing the need for occupational therapists to keep informed, with reference to advancement and the availability of equipment. This combined with other occupational therapy skills would secure the future of the profession:

"what we do as OTs we problem solve we're great detectives we'd also be good policemen I think because we look at a situation and we unpick and unpick and unpick" (Alex).

As for the future, Alex later referred to core occupational therapy values around the responsibility and duty to listen to the patient's voice:

"I think that we will still be needed whether it's bath boards and seat I think we will still need to support somebody to live in the home that they have chosen to live in and the way they choose to live so I think we will always be there but what we will be really good at is actually yeah trying to make it to help them to be as successful as they can be in [...] their life".

Other participants highlighted the need for future occupational therapists to become more creative and adapt their existing conceptual idea of equipment to one which viewed all mainstream gadgets and objects as viable therapeutic options. For example, Eddie referred to mezzaluna knives, which looked "quite fancy it's a bit Nigella". Whilst these were not identified as a 'disabled persons' piece of equipment, they can be utilised by all individuals for a range of kitchen skills including those with a functional deficit. This change in conceptual thinking relies on the attitudinal adjustment of the therapists alongside the service user population, some of whom continued to retain "*a sense of entitlement*" (Eddie). With items now more affordable than in the past, encouraging service users to purchase equipment provided they were not disadvantaged, would enable occupational therapists to focus their time on specialist equipment (Eddie). Several participants, including Eddie, were mindful how service users and others may be without sufficient funding or resources to purchase new technology and devices.

Alex recommended a future where meeting need would require occupational therapists "to be more savvy with technology" rather than retaining an exclusive association with the more traditional ADL equipment. Occupational therapists would need to be aware of the technology available and be able to advise individuals irrelevant of who is responsible for its provision (Alex). Jamie had mixed feelings about technology, they expressed 'horror' at the prospect of clinical interventions being robotised and dehumanised in the future. Equally however, they congratulated those who had "taken the initiative" and now used technology to enhance their lifestyles and regain some control and independence. However, as the world progresses and technology advances debate surrounding what constituted or defined 'specialist equipment' was raised. This was particularly relevant if the monetary value of equipment is used as a reference point for the decision-making process. For example, the cost of some equipment considered specialist is less than that which is currently available through statutory services or may already have been removed from the statutory list of provision. The need for negotiation and compromise is likely. Similarly, as service users become increasingly passive in their lifestyles and interact more with technology, Lee surmised how existing ADL areas may change indicating the need to redefine what constitutes equipment for daily living.

#### 4.3.3.2 Feeling threatened

Despite the participants' positivity around occupational therapy moving forward into the future Frankie and Harry approached it with a greater sense of disquietude. With a perceived level of regret Frankie and Harry discussed whether equipment would remain inherent to the role of occupational therapists or, as with other specialisms be

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integrated into other professional roles. There was a deep concern that the role of occupational therapists would be lost. Despite the idea that clinical leaders perceived professional integration and generic working as a positive step forward Harry believed "*the blurring of roles can be a little dangerous*" and implored colleagues to argue that not everyone is competent or capable of providing equipment. Frankie was more optimistic, indicating a need for a "*specialist level of knowledge*" which required "*a different level of competence*".

Harry became openly emotional at the prospect of others who lacked insight taking over the equipment role, it "absolutely terrifies me to death because they'll just give equipment out". Though there is the belief that additional monies will be made available for equipment it was anticipated that "every other discipline'll have it as well" (Nicky), they were clear about the repercussions:

"anybody's just gonna go at equipment and then it will have an effect on ourselves as because it'll be going out willy nilly and we just won't be able to get it' (Nicky).

With what could be perceived as resignation and a sense of foreboding, Nicky suggested *"they're gonna compensate for everything"*. This was in sharp contrast to the values of occupational therapy:

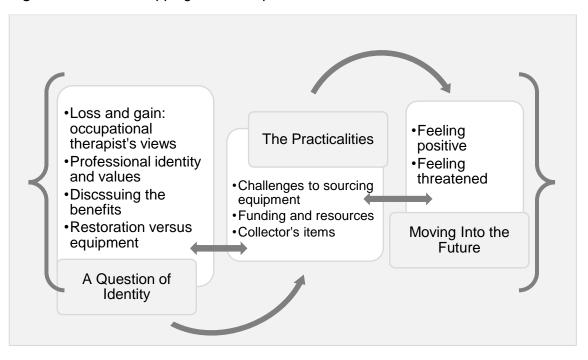
"we promote independence we're it's not just a quick fix we're doing it for a reason and we're aiding independence [...] we're giving the clinical reasoning [...] we're seeing the patient holistically" (Nicky).

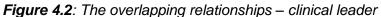
This section highlighted a return to the concept of professional identity, specifically how several participants were threatened by the prospect of others becoming providers of equipment. On the surface, Harry's comment around being 'terrified' suggested concern about equipment being issued by those who lacked understanding of its safe and appropriate use. Whereas underlying this was the concept of losing part of their professional identity to others. Equally, Nicky was as concerned as Harry at the prospect of other providers equipment. Similarly, to Harry, Nicky's primary concern related to a lack of knowledge and understanding and the reduced availability of equipment. However, underlying this was the knowledge that occupational therapy would lose the exclusivity of being an equipment provider. Whilst raising legitimate concerns over others completing elements of occupational therapy practice there was an underlying sense of the potential threat to the profession's identity and maintenance

of professional boundaries. For many occupational therapists the assessment for and provision of equipment is bound to the identity of the profession. It is part of what being an occupational therapist is. Several therapists perceived that the loss of this role and the identity it affords may lead them to question 'what is left'.

# 4.4 Reflexive thoughts and ideas

When evaluating my analysis, the six-step approach outlined by Smith et al (2009) offered a useful guide to format the structure of the analysis process and ensure the overall concept of IPA was followed. Equally, the flexibility of revisiting the data analysis process to address my concerns surrounding the 'contextual richness' (Ayers et al 2003) was helpful (see Section 3.3.9.1). By using this process, it provided the opportunity to reconnect the contextual value and meaning of the excerpts. However, whilst writing the analysis, I found further amendments were made to the selected excerpts as at times additional insight was gained and further interpretation required. In addition, as the writing process progressed the fluidity of the themes became increasingly evident and the ability to maintain them in a clear linear format challenging. As such Figure 4.2 represents the overlapping relationship between the subject of equipment, the super-ordinate themes, and themes. The overall process resulted in an in-depth analysis representative of the original data.





In terms of my learning, rather unexpectedly, I found multiple ways of interpreting meaning dependent on the selected excerpts and their position in terms of context. As

the excerpts could be viewed from different perspectives it was quite challenging to identify and effectively position any interpretations made. During the writing process, I found myself constantly re-evaluating my understanding of my interpretations against that of the original text and the participant's surface and potentially underlying meaning. I now recognise this as part of the hermeneutic process outlined by Smith et al (2009); this recognition though reassuring, remains challenging. Given this revelation, the need to stop analysing at some point is necessary. Otherwise, the analysis process become infinite.

At times, the volume of data was overwhelming, particularly when attempting to 'tell a story' and select excerpts that most effectively demonstrated the narrative being offered. Linked to this was the sense of growing responsibility I would feel in relation to ensuring authentic representation of the participants meaning making. Ensuring the voice of the participant was heard became more evident during the analysis cycle. Metaphorically, I believed my role to be likened to that of an advocate; my responsibility is to understand and be the voice of the participant who is currently unheard.

Though undoubtedly time-consuming, independently transcribing the interviews added value to 'doing' the analysis and report writing as my understanding of the premise of IPA was enhanced. Given the time-consuming nature of transcription and the sometimes, sporadic availability of participants, transcription was started before all the interviews were completed. Whilst it could be argued that the order of interviews and transcription may influence any subsequent interviews, I do not believe this proved detrimental to this main research.

Similarly, the process of analysis began during the ongoing task of transcription as discussed in Section 3.3.8. Though there is a risk of losing some of the participants' idiosyncrasies when audio recording only, I found that when listening back through the interviews (especially during transcription) I was able to regain a visual representation of the participants whilst they were being interviewed. As a result, I feel that some rather than many nuances, particularly body language and facial expressions, may have been lost. While I am aware of the selective nature of the memory, as an occupational therapist we are trained to be highly attentive and observant and recall our observations.

As a clinical practitioner who assesses for and provides ADL equipment using the same processes as those interviewed, recognising the importance of this, and taking

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steps to prevent it from affecting my analysis and writing was important. Whilst this 'insider' perspective is not considered problematic from a qualitative research perspective, being aware and mindful of preconceptions and addressing these is important. This is often referred to as 'bracketing' which requires the researcher to place preconceptions to one side. Conversely, it is argued that absolute bracketing is not possible and as such it is more important to recognise your preconceptions and discuss how this may or has influenced your approach (Smith et al 2009).

Maintaining the anonymity of the participants without losing the essence of the excerpt or its meaning was challenging. I underestimated the amount of time it would require to complete the analysis and subsequent reporting of my findings. Listening back through the interviews has highlighted several missed opportunities to explore in more depth some of the issues raised by the participants. However conversely, identifying when not to labour the point or ask for further elaboration is also a learnt skill. These specific skills will be developed during future research opportunities.

The experiences of the participants gathered through the interviews, the subsequent analysis and report reflects the premise of occupational therapy and equipment for activities of daily living from the perspective of the clinical leaders. In addition, it offers an insight into the clinical leaders' perception of the meaning of occupational therapy and equipment from the perspective of the user. There is also some understanding of the factors which impact on occupational therapy practice, their access to equipment and consequently the potential effect on the service user and their families. The participants who consented to be interviewed were all experienced in the field of ADL equipment assessment and provision.

Though the research remains focused on the role of occupational therapists and equipment for ADLs, the findings have called attention to the deeper and broader effects and impact of this. The semi-structured interview was developed to allow the participants to subjectively interpret the questions and express their individual experiences. Additional questions were asked dependent upon the topics raised by the interviewees as is an expectation of this form of qualitative research interview.

# 4.6 Summary

The findings of this chapter offer insight into the potential equipment has to restore and effect the identity of its users and those around them. Equally, it demonstrated how the provision of equipment had negative connotations on service user identity.

Furthermore, it highlighted clinical leader's perceptions of the role and purpose of equipment in relation to their own professional identities particularly when discussing equipment in association with other professions. The potential threat to professional identity was profound. Though the relationship between occupational therapy and equipment coexists, therapists do not view themselves solely as 'providers of equipment'. To occupational therapists, equipment does involve the restoration of occupations, however, it is also much more than this. It is fundamental to the profession as a means of restoring service user identity and evidencing the distinctive nature of the profession. If other professions are seen as equipment providers, occupational therapy is at risk of losing a major element of its professional identity. Given the participants of this main research project were all employed by the same Trust, it is unknown whether the concept and perception of identity is exclusive or transferable to other areas. When undertaking my original degree, the emphasis on equipment appears to have been less evident than that remarked on by the participants in this research. Understanding whether the feeling of becoming an equipment provider is contextual and or somehow linked to the panel process and the time this involves is not known.

In addition, the data analysis process raised questions regarding occupational therapy values and culture: specifically in relation to how these are impacted by enforced change such as policy and a professional perspective. Staff morale was identified as a key issue when considering the opportunities for accessing non-standard equipment and how the professional integrity of staff is challenged. The debate between using a restorative or compensatory approach is inherent and similarly linked to service user and therapy values. The lack of an appropriate outcome measure was of concern to the occupational therapists as was their ability to gather meaningful evidence of the impact of equipment and equipment services was poor. Several factors were raised, including the reliability of occupational therapy assessments in relation to the non-use of equipment. A shift in the culture of equipment provision is notable in relation to averting risk and how this fits with issues regarding professional ethics and responsibilities. With this is the undercurrent of a growing culture of over-prescription by some occupational therapists. The implication of equipment non-use on resources, the 'quick fix approach' to therapy outcomes and the effectiveness of occupational therapy assessment was raised. Whilst the participants may accept there are benefits to equipment provision in terms of a timely discharge, this shift toward a compensatory approach is not championed by all.

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Chapter 4 presented the findings of the clinical leader sub-group. Nine occupational therapists with a clinical leadership role were interviewed, they were responsible for managing other occupational therapists and therapy staff whilst holding a clinical caseload of their own. Three super-ordinate themes and seven sub-themes were developed during the analysis and writing stage of this thesis. Transcript extracts are used to support and evidence the participant's experiences and the researcher's interpretations. The following Chapter [5] presents the findings of the occupational therapist sub-group, and Chapter 6 that of the service users. Chapter 7 draws together the findings of each sub-group before integrating these into the wider related literature.

# **Chapter 5: Findings – Occupational Therapists**

The previous chapter (4) presented the findings of sub-group 1 (clinical leaders). It provided several of the researcher's reflexive thoughts before ending with a brief summary. Similarly, Chapter 5 begins with a précis of the participants' backgrounds followed by my perceptions of the interviews including the participant's engagement in the process. Using excerpts selected from the interview transcripts, the chapter then explores a range of topics arising from the super-ordinate themes and sub-themes identified during the data analysis process. Each super-ordinate theme begins with an outline of my interpretation of the shared experiences of the participants before presenting each theme in full. Further reflexive points are provided before a summary of the findings for this sub-group.

As previously discussed in Chapter 3, Section 3.3.5, all participants were assigned a gender-neutral pseudonym to help maintain their anonymity. Where required participants continue to be referred to as 's/he' to maintain narrative flow and where appropriate summarised information is provided collectively.

# 5.1 Participants

The ten participants within this sub-group described themselves as occupational therapists who held a clinical caseload with no leadership or management responsibilities. They may however have been responsible for supervising junior staff, including qualified and non-qualified colleagues. The length of interviews ranged between 25 and 68 minutes, with the majority taking place within a 50 to 60 minute time frame. The clinical history of the participants varied but collectively involved seeing service users of all age ranges and clinical contexts including inpatient and community. All the participants assessed for and provided equipment for ADL within the home environment as part of their role. Typically, service users had moderate to complex occupational performance needs caused by a long-term condition combined with the onset of an acute medical or surgical event.

## 5.2 Interviews

All the participants engaged during their interviews, however one participant (Pat) appeared particularly nervous. Consequently, Pat's responses were generally stilted and often lacked the depth offered by the other participants. Kit and Vic were nervous as both repeatedly questioned whether they had responded appropriately. Whilst Jo did

not appear nervous, s/he provided honest and to the point precise responses with little, if any, elaboration. When prompted, Jo continued to offer similarly precise and succinct responses. On reflection, in general, the participants' responses were often inhibited and therefore in an effort to gather a greater sense of their experiences I appear to have prompted this sub-group of participants more extensively than the last. It could also be suggested that opportunities to lead the participants also increased. I have extensively considered the cause of this in terms of the confidence and clinical experience of the occupational therapist participants compared to the clinical leader sub-group and feel this a likely contributory factor. Equally, the participants may have been concerned or suspicious about whether their comments might be used, particularly by the organisation they work for. In contrast, at times the occupational therapists' responses, though considered, were insightful. The exceptions were Mel and Ricky, who were confident throughout. However, despite both providing honest, articulate and insightful responses, during transcription a number of Mel's responses were found to be recurrent. Whether this simply reflected Mel's interpretation of the questions or a lack of experience is unknown. Sam provided 'to the point' responses, which were often contradictory and offered little elaboration of the experience. Whether this demonstrated the complexity of occupational therapy practice through their own experiences or simply Sam's response to how s/he believed they should, or the researcher would want them to is unclear.

Bobby commented on the timing of their interview stating how, had they been interviewed the previous week their responses may have been less positive. Whereas Glen, despite the anonymity suggested s/he did not wish to appear to be "going against the organisation". Though less evident during the transcribing process I noted a sense of careful consideration before Glen responded, however this was possibly observed through non-verbal cues as opposed to verbal communication. Despite their reservations, Glen was clearly passionate about the profession of occupational therapy and their role when openly voicing some of what they perceived as negative changes over time.

#### 5.3 Super-ordinate themes and Sub-themes

As Figure 5.1 demonstrates, three super-ordinate themes and 11 sub-themes were developed during the data analysis and chapter writing processes. As with Chapter 4, each super-ordinate theme is introduced before the associated sub-themes are presented and supported by transcript extracts.

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*Figure 5.1*: *Final set of super-ordinate themes and sub-themes – occupational therapists* 

# 5.3.1 Super-ordinate Theme: Restoration or Compensation

Using the occupational therapists' perception of their experiences the following superordinate theme recognises the notion of roles and identity in relation to family and service users. It explores the participant's sense of their own professional identity. It later provides an awareness of the positive and sometimes negative impact of equipment including the balance between provision and non-provision. This is achieved using selected excerpts to support the interpretation of the findings. The sub-themes are: establishing and re-establishing identity, equipment user identities, professional identities, outlining the benefits, and restoration versus equipment.

# 5.3.1.1 Establishing and re-establishing identity

Whilst discussing patient recovery following a potentially life changing event, and at which point to provide equipment, Bobby referred to the importance of:

"educating the patient around what's happened to them because that's the biggest thing cause they don't have a future unless you know what's happening to you or what's happened to you and why that's happened and what the difficulties are so the education is just as important as providing a piece of equipment".

Underlying this statement is the emotional impact of loss and grief experienced by service users as they begin to understand their current position. Without this 'understanding' the implication that service users may struggle to realise or accept the new 'them' and how this would fit with their future self and identity was evident. Equally, Bobby highlighted how for some service users their immediate post event identity may evolve as they progress through treatment whereas for others improvement is unlikely and the new 'them' is their new best:

"so it's letting them know that the equipment's may change throughout their abilities as they progress and that nothing is set forever apart from when it becomes a long term condition and they've realised they've deteriorated and this is the best we're gonna get so we have to maintain it".

Again, this excerpt implied a link between the patients' new identity, any equipment needed and how this may define them over time. Bobby revealed how service users' distress levels are heightened by the sudden need to use equipment and what this may signify for them. Whereas Bobby reinforced the need to talk about the purpose of equipment with service users to enable them to come to better terms with the need to use it:

"the education is important around it as well and that they understand why it's there and what's it for [...] they know how it should be used then they can inform others that are coming in how useful it has been and they can see a means to an end and they can see some ... err light at the end of the tunnel".

Here the act of informing service users of the purpose of equipment has the potential to allay fear and anxiety and offer a brighter perspective of the future and identity. As such, the consequence of not discussing these issues with the service user could have a profound effect on recovery and in return how they continue to 'see' themselves into the future. In contrast, Jo and Mel remarked on the use of equipment as a means of reestablishing roles and identity to the family as opposed to the service user. Often, family members assist relatives for significant amounts of time before asking for or being offered an alternative solution: "other than making them more independent and reducing the need for ...for carer support so if we've got somebody something they can get into the shower with it reduces the need ... for maybe mum and dad to help or for the support worker to help [...] maybe getting a bit more back as the role of the mum and sort of a friend instead of the carer" (Jo).

Here, Jo highlighted how the introduction of equipment where there are established roles is challenging, even where the intention of the equipment is to ease the potentially detrimental effects of some tasks and activities such as moving and handling. Where parents have continued to provide support after the time which may be naturally expected, is difficult to relinquish:

# "working with parents as well that's a big barrier from people who have gone through all the childhood lifting and carrying to then trying to introduce equipment to help them move the people".

Where activities become embedded as the norm, asking service users family members to change the way they conduct a task can be emotionally distressing. For example, family can be impervious to the damage lifting someone can do whilst also believing their care is being questioned detrimentally. In addition, for some, accepting they may no longer 'be needed' is emotionally inconceivable and invokes a sense of guilt as they no longer centre their full attention on their loved ones. However equally, Mel described how the introduction of equipment is a positive outcome for many family members as it allowed them to return to their preferred roles:

"I can't cope anymore we're really struggling to do it or I'm having to do this for them which is hurting my back like I'm having to lift them out of the bath so that hurts my back or I'm having to do my tea for my family then go round to theirs to provide them tea so if there's things that we can provide them that can like I said can they can do it themselves now then it means that their families can have a bit of peace of mind as well and they can kind of take back their quality of life so it doesn't mean they don't have to go round anymore but like they find that they're always there and it kind of takes away from what they want to do".

Mel's comments on their experiences reinforced how equipment had the potential to return a sense of contentment to family, as they are no longer consumed with the role of carer. This was in sharp contrast to Jo's experiences which highlighted the complexity of meaning attributed to ADL equipment.

## 5.3.1.2 Equipment user identity

Several participants raised the issue of service users' negative opinion of equipment provision, particularly due to their perception of how others viewed them. In their experience, this often resulted in equipment being declined as service users viewed provision as a form of personal defeat or allowed others to see they were struggling and by default less well or able. Intrinsically, they viewed equipment as 'disabling', a label for whatever reason they would prefer not to attach or be attached to themselves:

"it might make people feel like they're they are not managing as well if they need all this equipment in place or how or I think sometimes they think well I don't know that how other people might perceive them having all that equipment so family and friends and things if they feel like oh well so and so doesn't need that and I I've got to have it then they might feel a bit more disabled I don't know" (Kit).

The excerpt above signified how the suggestion of needing equipment may have a detrimental psychological impact on service users. Prior to a suggested need for equipment, service users either consciously or sub-consciously would have viewed themselves as independent irrelevant of the standard of their ability to carry out tasks and activities. The conscious decision to 'carry on regardless' demonstrates levels of resilience and the determination to continue despite arising challenges to continue. Whereas with equipment, either the suggestion or acceptance of provision, validates a deterioration in their ability. As an occupational therapist the 'carry on regardless' approach should be applauded and encouraged not thwarted by the provision of unnecessary equipment. Mel, Sam and Vic all agreed that some service users declined equipment based purely on who may see it and as such how it defined them. Ricky offered an excellent example of this:

"he didn't really want a stairlift and a big piece of equipment like that because that took away from who he was his identity he didn't want to be this frail poorly man he wanted people to come into his house and know him as who he was a funny man guy who liked a laugh and not this poor frail ill man and that was his perception of what equipment would mean to people that were coming to see him".

Kris further reinforced the idea of how equipment evoked a sense of 'change' in service users who preferred not to be labelled as either infirm or disabled:

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"people can have a negative association with equipment that makes them feel vulnerable and makes them feel old or puts em in the category of being physically disabled".

Both the excerpts above indicated service user's perception of how the provision of equipment altered their identity from one of youthfulness and good health to one of aging, deterioration and poor or declining health. This perception was not limited to older service users as Kris later described a younger perspective, particularly those with young families, who neither wanted the equipment nor "*want to be seen in that way*" [Kris] by their children. Kris inferred that as the younger generations age, the design of equipment would increasingly fail to fit aesthetically into people's lifestyles and by association compliment their sense of personal identity and how they would choose to be seen:

"the look of it all brown and beige I think as the younger generation are getting older they are not too keen on having this blue and white and brown and beige equipment everywhere it's not the most prettiest looking".

The above extracts represent the experiences of occupational therapists' perceptions of service user's experiences of equipment. However, as a generation of therapists whose expectations of modern aesthetics may differ from those of the past the potential for subconsciously imparting personal views onto others may influence our approach. As such are we guilty to some degree of transferring our aesthetic preferences. Unfortunately, whether this is the case or not, as Ricky stated, issues with the impact of aesthetics is not "*a priority of the NHS as a whole*", whose interests lay simply in its functionality. Alternatively, equipment aesthetics would be defined differently dependent on the individual perception and context. While for some, the topic of aesthetics referred to how well the equipment blended into the style and décor, for others their concern was more practical as the equipment failed to blend into its surroundings and as such raised feelings of vulnerability within the community:

"I think it's more if it's on the outside and everybody can see it's advertised a little bit more [...] just that there ... maybe got mobility problems or older and things like that" (Ricky).

Equally, whilst recognising service user's perceptions of vulnerability, cultural values in older people was an alternative reason for equipment rejection. Ricky suggested that pride in appearance of property combined with poor aesthetics deterred service users from accepting equipment:

"but I think as well it's the culture of the older generation it's always making sure from the front your house looks a certain way take great pride in that".

Strong emotional and historical ties to a property was a high motivational factor for some service users. Remaining in a known environment surrounds individuals with the familiarity of their past. It enables the continuance of established roles and represents and maintains a sense of identity. The physical environment and the objects within it tell a story and offers insight into roles, occupations and relationships:

"the positive side for some people is that if they've come in from they've come into hospital and they want to go home and they only want to go home so if you can put a few bits and bobs in their house that means that they can continue to stay in their own home they've lived in for so many years with their partner as before that it's a real positive on them because they can still continue even though they've had this illness they can continue then then cause you're going down the route that they want that's their quality of life" (Mel).

Where service users are concerned about how they are perceived by others, finding a solution often requires compromise and negotiation and alternative equipment which is considered portable and the least invasive. Ideally, equipment should complement the service user and be perceived as a tool to maintain rather than obstruct identity.

# 5.3.1.3 Professional identities

Several participants highlighted the embedded nature and identity of occupational therapy practice and equipment provision. Mel suggested the relationship between occupational therapists and equipment begins during professional training and remained a fundamental element of job interviews and induction:

"I think it gets drilled into everyone but I think as it's being part of us from the day one of start of training and I think it's kind of it's almost like in your introduction when you go for job interviews usually one of your answers is involving some sort of equipment because it might be a scenario and then you're eventually gonna chuck in a bit of equipment there as well and I think that's what they're looking for but I think yeah from just start of studying and things I think it's always kind of drilled in and that's why it's kind of a it it's part of us".

Mel's repeated use of the word 'drilled' in this excerpt is interesting. Namely, that during pre-registration training equipment is identified as a meaningful primary occupational therapy intervention in its own right. Alternatively Mel implied that repetitive reference

to ADL equipment resulted in it becoming the norm. As such it is unclear which is the cause and which the effect in relation to the ongoing association between the two. This imprinting of equipment provision is learned by other professions who, according to Mel, immediately deferred to the occupational therapist should a potential need be raised:

"when you start kind of your job I find that like physio's kind of do their bit they do their mobility their transfers which we kind of cross in and out of they look at strength and movement and then if a patient asks them anything about equipment it's physio's will say that's what our occupational therapist is for let me get them involved or I've found that a lot of the time on the wards patients might say to the nurses in passing oh I struggle to do this or I struggle do that and then they'll say we'll get our occupational therapist involved cause every I think I think it's drilled into everyone that that's what we're for".

Thereby if the occupational therapy profession itself, whether intentional or not, impresses an equipment connection on itself, by default, others will perceive the same. As such equipment becomes and remains integral to the identity of occupational therapy and therapist practice. It is therefore recognisable how some occupational therapists are threatened by challenges to the 'establishment' of equipment as belonging to the profession. However, in contrast, Sam suggested the profile of the profession is increasingly recognised as being about more than equipment. To underpin this shift in professional reasoning, Sam actively draws attention to other types of interventions and skills used by occupational therapists in practice:

"I think more people are aware of occupational therapy I don't know if it's because people see us around on the wards I'm quite engaging with people that come visiting I'm quite happy to talk to family and explain what we've been doing and how the patients progressed or if we've maintained or and I'd tell them what we're interested in that we're interested in function and the activities that that persons interested so I'm always interested in finding out what they were doing at home can we kind of emulate it some somehow in the hospital so I think by talking to people it kind of people are more aware of us I think with regards to I don't think they see us as just dishing out equipment and I think that was the picture people would have had a while ago I think now I think they're aware that we do use techniques as well the equipment provision is still there but it's not the be all and end all".

Sam appreciated the knowledge that others awareness of the purpose and potential for occupational therapy was improving, and that they were playing an active role in this process. The benefits of this type of interaction on the ward widens and enhances the

role of the occupational therapist as being more than 'just equipment'. In contrast, with reference to generic working, Kris was concerned about the change of landscape causing detriment to and a loss of professional identity:

"I think there's a lot of role merging going on so there's a lot of cross training so other professionals are able to ... do some of our job roles so it's still maintaining our boundaries of what this is our professional remit this is what we do compared to what other professional do so [...] it's good because we're able to cover other services when they're not able to and give better patient care but we just don't want to lose our identity as OTs".

The benefits of professions 'covering' for and assisting others, such as occupational therapy and physiotherapy has history. For example, many occupational therapists will have issued walking frames as will physiotherapists have provided RTS. As such the benefits of some cross over of roles was not lost on Kris. When asked directly how occupational therapy can prevent a loss of identity, Kris replied, "*I suppose just defining our … key skills and keeping ownership of them*". However, in their interview Kit stated that whilst it may be acceptable for high level equipment provision to form part of a generic working pattern, professional specialisms including low level specialist equipment should remain and clearly be defined as profession specific.

Despite acknowledging a certain level of ridicule both within and external to the occupational therapy profession, Ricky defended the relationship between them and equipment. When considering the future, s/he highlighted the ongoing long term need for equipment and the underestimation of its benefits:

"I think there'll always be a need for it and I think they're often kind of mocked a little bit oh here comes the OT with their raised toilet seat [laughs] and it is it's kind of an inside joke of that's what we do we provide raised toilet seats but they do make a huge difference to somebodies life and they are very much needed at times so yeah I do think they will still be as required".

## 5.3.1.4 A sense of dignity

All the participants in this sub-group referred to equipment as a method of enhancing service user, family and carers' quality of life by improving independence through engagement and participation in meaningful activities. Several participants identified the contrast between the positive and negative benefits of equipment provision. Beside issues such as the promotion of independence a common underlying topic involved the

participant's perception of service user dignity. For example, Bobby referred to maintaining the dignity of their service users as one of the key benefits of equipment commenting particularly on one individual who was "*absolutely mortified*" at the prospect of being assisted to and from the toilet. As a result, the service user and therapy team concentrated on independent transfers to and from a commode. Similarly, Pat referred positively to patient's use of commodes:

"sometimes if we provide things such as commodes things like that it can be for dignity reasons as well so that instead of not making that distance to their toilet they're still able to go to a toilet and meet that sort of need ...".

Though contextually different, both Bobby and Pat recalled their experiences of the provision of commodes as positive. With one service user choosing to use a commode to promote their independence and in turn their dignity whereas others simply to keep their dignity intact. Ricky highlighted the multiple benefits of equipment provision including the potential to improve service user's dignity:

"I mean it's obviously promoting that independence to an extent but I think more than anything it's a bit of dignity as well once patients are off the ward and things it is as much as we try it is still quite an undignified environment wards are unfortunately it's communal living [...] being able to get home and have that bit of privacy and manage to the best of their abilities just helps a little bit with that".

However, here and as highlighted previously in Sections 5.3.1.1 and 5.3.1.2, personal conflict surrounding service user's acceptance of equipment exists:

"things such as commodes which .. can affect dignity cause it's quite a private thing isn't it a lot of people do decline things like commodes because for that reason I would say [...] it could be how they look or just the fact that it's a piece of equipment they wouldn't normally have to serve that function such as the commode in in their homes somewhere separate from where they would go in the bathroom" (Pat).

"people can be a barrier sometimes if they don't like the look of the equipment if they have regular visitors and they don't want people to know they're having problems with x y and z you know like a Mowbray toilet frame would be a rather obvious addition to your bathroom if you're wanting to be discreet" (Sam). Here, underlying the topic of service user's dignity was the attempt to protect personal identity. The service users did not wish to be seen differently to others. The need for equipment altered their health and functional status which they preferred to keep private from family, friends and neighbours. Sam suggested how equipment enabled participation in activities and as a result facilitated independence which negated the need for assistance from others. This, whilst not stated, resulted in a positive impact on issues such as dignity and re-establishing service user or family roles:

"equipment would be issued to enable them to participate and to increase their independence so for instance it could be a shower chair because the patients not able to stand to shower because of either balance problems or fatigue but is able to wash themselves so the shower chair would be provided so that they've got sitting rest and it could be used alongside grab rails so that they could stand at times that they needed to but then obviously have the chair there to rest and that would prevent them from having to have carers or nurses assist them in their in their washing which is quite a personal task" (Sam).

Likewise, Ricky's experiences highlighted how equipment provided support to informal and formal carers which reduced both the physical and psychological effects of assisting individuals to complete activities. Whilst Ricky recognised the combined need for equipment and formal social care is increasing this was not to the detriment of the service users. In fact, the alliance of the two enabled the service users to be *"functioning to the best of their ability"* (Ricky) which then had a positive effect on quality of life and how they viewed their future.

Ultimately, the purpose of equipment is to empower service users who are not at their best, to be as able and independent as possible. Several of the participants, including Bobby, stressed the importance of equipment on service user's mental well-being as well the physical:

"you're giving them back their independence which a lot of these patients don't you know they're traumatised it's gone they're vulnerable and trying to give them as much independence helps their well-being brings on their motivation keeps their occupation going and gives them a future ... keeps them going".

Similarly in their role, Glen described the benefits of equipment as an opportunity to provide independence, purpose and routine, particularly to those who may have participated little in activities for some time:

"re-engaging people in activity because a lot of people with pain stop moving so they have the fear of movement and then become very low in mood and very low in energy [...] is about trying to re-engage people in meaningful activity so providing a perching stool if it's gonna get somebody back in the kitchen or providing some bathing equipment if it means that somebody's going to start doing something for themselves again and doing something independently that's what I would be looking at".

Participants also emphasised the impact equipment had on the "*psychological well-being*" (Glen) of service users rather than just the physical implying the two go hand in hand. Bobby highlighted the positive impact of equipment on service users and families. Bobby described how the provision of specialist seating enabled one service user to actively engage in activities with peers and family, thus increasing opportunities for social and domestic interactions:

"had this very rare condition and had no muscle tone what so ever [...] one served as a rest chair and the other one was more functional to actually to interact with his family both were vital for his occupation throughout the day [...] and the active chair more functional chair meant that he could go to the floor level and actually be at the same height [...] and have that same level with his peers and that communication that interaction and then in the evening he could be at the table with the rest of the family instead of being down low and not even in the same room health and well-being for the family as well as the patient" (Bobby).

Most participants recognised how smaller, less specialist, items of equipment such as pen grips "*means everything to some people*" (Bobby). Similarly, Glen stated how "*the smallest things sometimes make a really massive difference*", even to those who were initially "*sceptical*" of the potential benefits. Likewise, Kit, Kris, Mel and Vic perceived how simple pieces of equipment such as trolleys and shower chairs had an impact on independence, service users being able to remain in their chosen environment (i.e., their home) and social engagement within the home and the wider community. For example, the ability to transport items from one space to another offers patients the opportunity to "*maintain the meaningful things that they like to do*" (Kris). Equally, equipment facilitated personal care tasks which in turn incentivised opportunities to meet with friends and family:

"if you struggle to get yourself washed and dressed in the morning well we can provide those things where you are more likely then to want to go out and see your friends because you you're still kind of functioning as before" (Mel). All these examples support how equipment provision maintains dignity, a sense of identity and reduces feelings of being burdensome. Equally however, Mel proposed how the consequence of equipment provision could be psychologically catastrophic resulting in a spiral of declining function caused by a generic misconception that accepting equipment implies a "*can't do it for myself*" attitude. This negativity resulted in a self-perpetuated lack of engagement in an increasing range of activities and tasks which ultimately compounds and facilitates a reduced ability to perform occupations. In contrast, Vic highlighted how equipment could provide a sense of control which leads to an improvement in well-being:

"I think ... it improves well-being ... just because they're having more control over their life maybe with the bits of equipment that we're able to give and ..... something that they might not have had for a while and we just give one piece of equipment and they're able to do loads of different things".

Jo highlighted how the benefits of equipment provision did not just involve the physical element of function but rather a need to be holistic and more flexible in your approach. An example provided by Jo outlined the multifactorial elements of equipment provision including: the psychological impact on the patient and family, pressure to conform to societal norms and ultimately preventing a breakdown in family relations:

"it does make a big difference I mean just something so small so I had a lady who wouldn't get in the bath cause she had a fear cause she had a fall and she just couldn't get over that and just providing a bath lift she probably doesn't physically need it but for her confidence to get back in and out of the bath again for a short period of time use that as like a rehab tool so that for and her family made a massive difference because the stress of not getting in the bath or the shower was causing it was causing mum a lot of stress and arguments and it was their life was revolving around it so it can have a massive difference [...] it was terrible for her mum and her family that she wasn't particularly all that bothered the lady but her family were getting on the mum about it about the fact she wasn't bathing and she was looking untidy and wasn't smelling very pleasant and then her mum was getting on at her which was having massive effects on the lady so there was yeah there was massive a break down in the relationship between her and mum".

Here, the outcome of being 'holistic' rather than prescriptive enabled the service user to begin to bath and regain their confidence in the occupation. Equally, though the service user may have been unaware of the family concerns, their (service users) dignity was

restored from the perspective of the family. Ultimately, this flexible approach benefitted all of those involved.

# 5.3.1.5 Restoration versus equipment

In this sub-theme the role of equipment was disputed by the participants and its relationship between the complex choice and factors of provision and non-provision. Furthermore, it extended the conversation introduced in the previous section (5.3.1.4). Although the participants championed the advantages of equipment, many acknowledged its place as one option of many occupational therapy interventions. For example:

"use as less as possible [smiling] less is more [both laugh] well you know you don't want to introduce something unless you really have to [...] I would rather work at their best and get physically as well as they possibly can and I always say it's a means to an end it's to get you from a to z but this piece might take you from a to c and we'll relook at it" (Bobby).

Similarly, Glen referred to equipment as a secondary intervention. Glen identified it as an approach which encouraged self-management as opposed to one which implied disability and dysfunction which is or becomes reliant on equipment as a solution:

"my role is much more about educating people in self-management strategies and looking at psychological well-being so provision of equipment is almost a ... oh what's the word I would use ..... is a means to an end and it's actually I don't do an awful lot of it in that sense because as I said previously a lot of my clients or patients are quite mobile and I try to keep equipment provision to a minimum ... because what I'm trying to do is help people to live [...] I don't want them to be I don't want to be saying you're disabled which is a lot of the equipment feels it labels people as disabled and actually what we want is for people to be thinking yeah I've got this [...] condition but actually I can live as normal a life as possible so I try not to get too involved in equipment provision".

The two extracts above emphasised the role of equipment as important but that it should not be the emphasis of clinical practice and interventions. Glen's focus was 'living' with a disability as part of your identity but not one which is your identity. Glen believed the provision of equipment shifted the focus from being a person who is living to becoming a person who is disabled. As such, both Bobby and Glen opine that equipment was useful but not always necessary. There was, however, a difference in professional opinion. For example, several participants implied a sense of obligation or

a pressure to conform, which combined with a lack of experience 'fixed a problem' which was not understood and ultimately leads to over-prescription:

"it's a bit of [...] a pathway driven thing isn't it ooh this patient's got x condition therefore they need y piece of equipment not this person is an individual and let's see what that individual needs" (Glen).

Whereas others identified with the pressures different services encountered and the type of challenges experienced by the service users. Jo implied how therapists were pressured into holding a larger case load compared to those in other services. As such, due to time constraints there was less opportunity to consider alternative creative solutions which ultimately would result in the provision of less equipment. Jo, Kit, Mel and Pat all shared similar opinions on this issue. The implication here is that service remit defines the volume of equipment provided. This is particularly the case where there is pressure for safe, timely service user discharges and which prevents readmission compared to one where the emphasis is on rehabilitation. As such, pressures within a service result in an immediate shift between interventions with a rehabilitative approach to an adaptive, compensatory one. Equally, there is a psychological impact to focussing on equipment as a part of initial discussions and primary interventions before the actual clinical need has been established. As Mel stated:

"you're kind of telling them that they're needing this before you know they truly need it sometimes ... so like you kind of put them down before you're given them a chance to prove themselves" (Mel).

The topic of conflict between the choices service users make and professional ethics and values is also evident. Accepting service user's choices, which may be considered unwise, are at times challenging to understand and accept. For example, while many service users embrace equipment to enhance their quality of life and reduce dependency, others:

"don't want to participate in using that bit of equipment they would much rather be hoisted" (Sam).

Understanding service user's motives for choosing to use equipment over functional improvement or maintenance is complex. The ability to understand service user's choices is important. For some, the use of a hoist over other moving and handling

equipment may be less invasive from an environmental perspective or cause them less pain/discomfort or fatigue. As such, though a hoist may increase dependency it likewise enhances the quality of life of that individual. Thereby, the service user has the opportunity to be themselves and maintain their sense of being through the use of and their perceived benefits of equipment. Alternatively, service users do accept equipment without full consideration the long-term implications of their choices on health, wellbeing and ultimately a greater reliance on equipment in the future. For example:

"some people want loads of equipment and [laughs] to make things easier but in a way that might be disabling them cause it might be taking their independence away cause it might be making things easier but by making it easier they might not be I don't know using their muscles and things to stand up" (Kit).

Occupational therapy practice is a skill which is learnt with experience over time. As this sub-theme suggests there were multiple forces at work when therapists are considering the provision of equipment and the service user's rationale for accepting or declining it. Kris and Ricky perceived clinical reasoning as a significant skill when attempting to balance provision with non-provision. This was particularly evident when occupational therapists managed service user and family expectations:

"just because somebody say's they think they need it or the member of the family thinks they need it doesn't necessarily mean that they should have it so it's finding that balance that the patient does need it and this is my clinical reasoning for them to have it and this is my clinical reasoning for them not to have it" (Kris).

Paradoxically, dependency and over prescription of equipment is created when clinical reasoning is misaligned with the concept of positive risk taking:

"K: if you was going to be positive risk taking then that was would have to be in a safe environment with professionals there that are able to intervene so I suppose it's a bit like in therapy so if we were walking again that is that if we were gonna progress a patient from ... a quad stick to palm to palm then that would be positive risk taking cause if we were there but somebody would be close by just in case they had a err topple or lost their balance they would be able to support the patient but not in their own environment without the correct support at home cause that's putting the patient in danger

R: what about if they lived alone

*K*: no I wouldn't put em do positive risk taking then I would I wouldn't over compensate on equipment I'd put equipment in that will support them I

would put in the correct amount I'd have to look for something else like a pendant alarms or fall ... [mumbles] and then make sure they've got other people's services coming in to support them at home" (Kris).

In this instance the participants understanding of positive risk taking was counter to the way this concept is understood within the occupational therapy profession. Whilst there is a duty of care to prevent harm this should not be to the detriment of service user's capacity to improve and more toward goal achievement (RCOT 2018b; 2021a). Whilst initially, it would be appropriate to assess service users' ability to progress in the presence of therapy staff, where appropriate to enable and facilitate progression it is necessary for the process to continue in the absence of staff/others. Progression typically occurs in the direction of the most to the least restrictive option, for example from a shower chair to a shower stool to no equipment. The intricacies and balance of equipment provision is often challenging and certainly not prescriptive.

## 5.3.2 Super-ordinate Theme: The Practicalities

The following super-ordinate theme discusses the challenges occupational therapists face within clinical practice and the impact this has on them and the service user. In addition, the participants raised issue with some of the pressures services face and offer opinion relating to equipment non-use and non-return. The concept of service user safety is also introduced with a particular emphasis on therapist's confidence of this issue.

## 5.3.2.1 Challenges to sourcing equipment

Bobby's perception of national policy and criteria was one of disparity:

"I know across the country it's different services depending whatever region you're in depends on what equipment they can eligible to provide they have set criteria's and whether you meet that eligibility for that piece of equipment".

Bobby recognised a national set of criteria would be challenging due to different needs in local populations. And, whilst local criteria were generally accepted by the participants some inbuilt flexibility would be welcomed to allow equipment considered patient centred to be sourced. Bobby implied that at present the constraints of accessing individualised equipment appropriate to clinical need is lacking: "I think that it's always going to be cost constraints and there's always the argument of should the eligibility cause eligibility the criteria is very different in every Trust you go to is very different and is it because it's the type of population in that area they're having to deal with that I mean I'm aware there's pockets of in our area where we have more of a minority and who caters for that well you know it's a bit of everything it you see the patient an individual and it's making sure that they get that right piece of equipment" (Bobby).

The lack of national policy or guidelines related to the provision of equipment was highlighted in Section 1.4. Though not explicitly stated, the detrimental consequences of changes in local policy and criteria were perceived by several participants, particularly in reference to service user's ability to engage in meaningful occupational activities. Specific reference to the smaller items of equipment was common, largely kitchen equipment. Glen's dissatisfaction and concern for the service users involved was clear:

"there is less small items of equipment available now and actually for some of the people that I see sometimes the little the small items of equipment that might get somebody back into the kitchen doing something are no longer available and some of the people I see where I think those would be really useful they're not going to buy their own so I think that's sad in in in that sense although I do give people catalogues and show them things and I'll show them things you know on I'll look I'll Google things and show them pictures of things that are available but obviously that means people have to go out and buy things themselves and sometimes that's a barrier to them then getting them and it's a barrier to them actually then participating in an activity".

Additionally, the 'barrier' referred to by Glen demonstrated the emotional impact this had on therapy staff when referencing their (Glen's) feelings of sadness on behalf of their service users. Underlying this was the impact local policy and criteria had on the scope of core occupational therapy practice in terms of preventing service users from engaging in their chosen occupations. Sam mirrored several of the issues raised by Glen:

"sometimes it's just the little things that keep that independence going [...] we did used to provide small items like grab sticks and things like that and then it got to that that particular Trust didn't provide anything under ten pounds they thought patients could err you know get their hands on equipment that was under ten pounds [...] which is alright for some people but other people might not have any support system to be able to they might

be house bound they might not be able to go out to the shops and get that simple piece of equipment that would help them get into bed safely" (Sam).

Historically before the advent and implementation of strict criteria and locally developed equipment catalogues, the opportunity to search for and consider the functionality of equipment was highly valued:

"in the past you'd go into the stores and look and say yep this piece of equipment will suit my patient whereas now it's a little bit more you have to have the equipment that's been chosen in a range whereas in the past we would say actually I'm going to search for exactly the piece of equipment that this person needs and request that we buy it if it's not or I'll look in the store and think oh yeah that fantastic at the bottom of this pile of stuff there's something that's just right for this patient and obviously it's not like that anymore but so having access to a catalogue where you can actually have a look and try and try and see what the equipment is like we do have that at one end again we don't have it at the other end of the patch but I still don't think that replaces actually being able to go and touch and feel and try and see and just work out and practice with it and think right my patients able to do this or they've got a restriction here or whatever and would they be able to reach that or what they work quite right or I don't I like the to be hands on and feel it and that's not very easy to do anymore" (Glen).

The removal of small items of equipment from the statutory provision list and the scope to request a wider range of equipment has reduced the opportunity for occupational therapists to be as creative in identifying potential solutions for service users. In the past, it was feasible to 'go to stores' with something in mind that may suit the individual but until you were able to 'look around' the solution was not always clear. The tightening of provision and stores not storing equipment as they used to has had an impact on occupational therapy practice. Equally, the opportunity to try equipment as part of an occupational therapy assessment or trial is now also lost and may be a contributory factor to the volume of unused equipment items.

Several participants spoke passionately about the process of sourcing non-standard equipment via a 'panel process' which they stated consisted of an unknown "*group of people*" (Jo). The process was typically described as lengthy, particularly where more expensive items of equipment are involved, and which frequently resulted in service users privately purchasing. The exasperation felt by many of the occupational therapists was clear when they implied those making the decisions lacked empathy or understanding of the issues raised and the solutions being requested. As Jo suggested, occupational therapists felt undermined and dissatisfied:

"sometimes I feel like you're begging for it [...] all we're trying to do is the best [...] I find it quite frustrating because to us it's something that'll really really really help and sometimes I feel if they actually saw how these people weren't managing ... then they might be more forthcoming with the budget" (Jo).

In addition, the participants perceived an absence of understanding by panel members, particularly those who are not occupational therapists by profession, of a holistic approach and the rationale for supporting clinical need:

"clinically reasoning things with people that aren't occupational therapists perhaps is quite difficult sometimes if they can see that they're using something but not quite getting the holistic picture of why something else would be more beneficial to that patient [...] ... but no there were a couple of instances there was a lady who needed a bariatric four wheeled walker ... and that would not only help her physically but mentally as well cause she would be able to get outside and so there was a lot of questions around that why she needed it and really was it necessary could she not have this that and the other and no it was she needed that piece of equipment because that would then enable her to have a seated rest if she needed it so it was yeah not looking beyond the piece of equipment not looking at the person as a whole" (Sam).

Furthermore, several participants expressed a sense of professional failure in their own clinical practice and reasoning when panel requests were refused or challenged:

"I think when you feel like you've put good clinical reasoning down and it gets knocked back ... you feel disappointed you feel like you have I missed something have I not explained it clear enough you can see the benefit that this patient it would have from this piece of equipment but you're not quite I don't know if selling it's the right way to put it but you're not getting your point you're not getting the picture across to those who make the decisions" (Sam).

The disparity of equipment provision across the three Trust sites, relevant to this research, linked with the accessibility of equipment and the panel process, further highlighted the clear frustration felt by the participants. The need to demonstrate clinical reasoning to the nth degree because of a service user's postcode was evident:

*"it was quite challenging it was quite difficult obviously ... because in [name] you can you can get it's quite hard to get Buckingham caddies here but at [name] you don't need a panel request for them ... [...] you can just order* 

them so that was quite frustrating because our one I thought this patient could for example this patient would benefit from one had to wait probably one or two months to just to actually get them one to assess them with which is quite frustrating when you feel that a patient would benefit from that" (Kit).

Despite their apparent frustrations, several participants (Bobby, Jo and Kit included) did acknowledge the finite resources available. However, Sam referred to the provision of commodes when expressing their lack of understanding of the rationale for these items being for short term loan only. Sam mused whether the criteria for one area of clinical practice such as orthopaedics, where there is an expectation of recovery and therefore the equipment to be a temporary provision, has crept into and evolved to include other areas. Furthermore, Sam highlighted the poorly judged assumption that all service users find equipment inexpensive to purchase:

"if you don't have a great deal of money then everything's expensive and if it's something that you need to keep you safe say overnight then it's invaluable".

Equally however, for some participants equipment provision was about ensuring the correct item was procured irrelevant of the funding source. Where offered, taking advantage of alternative sources was welcomed:

"it's making sure that they get that right piece of equipment and if there isn't is there a solution for it where you can get that solution like I say with a family member might be willing to purchase a chair like we had one last week what wan wanted to buy the chair so and that's where you take the opportunity to you don't abuse your stock" (Bobby).

## 5.3.2.2 Funding and resources

Whilst acknowledging funding constraints which impact on equipment availability, Bobby expressed their frustration of the effect this had on service users and their families. On the surface this dissatisfaction indicated a certain level of irritation surrounding the availability of equipment however, beneath this lies a deeper level of anxiety and distress which manifests as misplaced anger:

"we do need to have that flow of equipment and it can frustrate family patients when we can't get the right equipment at the right time to go home but bearing in mind there are budget restrictions we are looking at the big population and it's not just that their family member it's not just their patient they're generally very patient and they're generally quite good but there would be the odd occasion where somebody gets happy but unhappy but I think it's a lot a lot of around what's not it's not just the equipment I think it's the whole stress about the whole thing of going home of what's happened to the family that their family member or the patient them self it's they focus all their energy on something what's not going right rather than what's going well" (Bobby).

The impact of delayed provision from the perspective of the occupational therapists and the service users was evident. Whilst there was a clear acknowledgment of the emotional and physical impact on the service user, equally there were unaddressed implications to funding on host services in relation to delayed discharge:

"it holds up discharge it makes the patients depressed and not responsive they're getting angry cause then they're not sure why they're not going home why they are not able to go home and plus if the service goes over six weeks then they can get charged for staying here" (Kris).

The lack of equipment was typically associated with the end of the financial year; a point reinforced by Sam and Vic. The following excerpt further emphasised the consequences of limited or no available equipment on the physical well-being of the service users. It further underlined the therapist's sense of immediate discontent at their perceived inability to achieve a positive outcome which meets the primary goals of the service user. The unspoken yet longer term effects on moral and ultimately job satisfaction could result in major implications to the individual therapy staff members and the organisation, particularly in terms of recruitment and retention.

"sometimes there isn't the equipment there neither the stock or ... like yeah mainly like sometimes stores runs out like mainly after Christmas like bef the end of the financial year so then we're either substituting or ... they have to go to rehab or something if or go to attempt to try and ... progress them cause if they can't go home they might go to a care home or if they stay in bed because there isn't the equipment for them to go home safe [.....] it's not very nice really it's if they could if they could have gone home with a one or two pieces of equipment then it's sort of a shame and like we've let the patient down even though it's out of our control when don't control the budget" (Vic).

The sense of contempt for those who are perceived to lack empathy with and compound the challenges associated with the lack of provision was clear. The disconnect between face-to-face interventions and senior managers and other professions blasé attitudes was evident:

"I think the managers sometimes if they're not on the ward kind of get like out of the zone of being working with patients and realising that when they're saying no to something or if they're ... just saying well they'll have to go wherever there are out of the loop of what it's like to work with patients and see what how it's affecting them and being the one to tell them that there isn't the equipment or if you've got to go here for so long [......] it's general for people that aren't on the wards all the time so even therapy managers sometimes definitely erm ..... mmm ..... erm ... like the nursing staff like if we're waiting for equipment they're or they just they just send them home anyway on a weekend when we're not here so then we have to chase up and make sure they're okay and get community to go out pretty quick" (Vic).

In contrast, Glen asserted the importance of talking through equipment options with service users but equally accepted it is not necessary to offer all of these through statutory services. Glen opined that the inability to afford something different is not dissimilar to the choices and options we make in daily life:

"I think as long as you can give somebody the options and say this is what I would recommend because I think this will make life easier for you for this this and this reason and then you can say you can have one provided for you by the state and this is what it will look like or you can privately purchase one [...] people are can make the choice if they can afford to make that choice and I guess that's like anything isn't it if you're ... if it's being provided then it will be the best value one that will be provided and not necessarily the most aesthetically pleasing [...] you're gonna provide something that is quite ... utilitarian aren't you and then if somebody wants something different then they make the choice to then get that but I would try and help that to be an informed choice".

Whilst Jo recognised the national lack of funding generally within equipment services, namely assisted living centres or their equivalents, they were concerned with what they perceived as local disparity between paediatric and adult services:

"the transition from child to adult services and the funding there is a massive problem [...] they (children) get a lot of funding through social care and they get funding through education as well [...] they get to sit in a school chair they get to sit in a specialist wheelchair they get to go home and sit in a home comfy chair and a pea pod and it's all moulded to them and their postures lovely and then when they get to adult services because we have to fight for budget and there isn't the budget and we get rejected for things that's when everything deteriorates so they get all that while the bodies growing and up to the age of 18 and all that postural support and 24 hour postural management and then we get to the age of 18 and they say sit in your wheelchair and that's our answer on panels they can sit in their wheelchair they don't need this they don't need that they don't need the other they can go to the day centre in their wheelchair they can go in it straight away in a morning go to day centre come home and sit in the wheelchair sit by the dining table in the wheelchair so that I think is appalling ... and that's when we start getting deterioration in posture reoccurring chest infections pneumonia and death and the posture just goes from lovely ... to slump slump slump and they end up leaning to one side and then their organs get affected by that [...] that's where we start getting our real problems" (Jo).

Here Jo expressed their anger passionately at what they perceived as an inequality between differing life stages. There was no sense that as a child service users should be denied equipment which is clinically relevant, rather that there should be equality of funding to support equipment needs throughout all life stages. Jo challenged how it could be considered acceptable for adults to be seated in a wheelchair for extended periods of time. A decision which, whilst not stated explicitly, implicitly affected service user's ability to mix with and engage as effectively with peers or the environment. The social isolation experienced by service users was further highlighted by Jo:

"just stay in that from when they come home from day services till when they go to bed at night so what they have to do then is go for periods of rest on the bed of course that's not providing enough support so then they have to go into the bedroom in a supportive living environment where there's three other people sat in the front room ..... frustrating" (Jo).

Jo later compared the cost of equipment provision against that of preventing hospital admissions and pharmacological interventions. Additionally, a reduction in psychological distress and anxiety accompanied with increased morbidity was highlighted.

Several participants place patient need, safety, and the service users desire to return home above that of funding and resources of which not to do so is unacceptable. Kit stated:

"it's more what the patient needs and if they and if I feel they need and there's reasoning for that equipment then and if the patients safe to use it and we've assessed for that then I would go ahead and order it I wouldn't think about the cost implications necessarily". Whereas Mel was more direct:

"I don't think of the cost at all then I think if they need that equipment it doesn't matter what it might cost us as a Trust cause I think if they need it to get home and be safe we shouldn't be thinking oh we can't give them that because of the cost of what it will be on us I don't think that's fair".

Similarly, in common with Kit and Mel, Pat agreed in principle with the view that service user's needs should be the primary equipment driver. However, Pat asserted that funding was a consideration due to insufficient resources and how some creativity to stretch resources was required:

"their abilities cost isn't something that's on the forefront of our minds but then we would have to think about we couldn't give it to everybody so it's what's appropriate for each person but we do sometimes have points where we don't have equipment in stock so we have to consider other equipment that's available ... so that that there is sometimes a problem of cost but it's not something we would if a patient needs it we try and finds ways to make sure that they've got their needs met".

### 5.3.2.3 Collectors' items

Similarly, to the findings of Chapter 4, the non-use and non-return of equipment was highlighted by several participants. The reasons offered were varied and at times contrasting. Commonly, despite being informed of the conditions of loan, which includes the prompt return of equipment no longer in use, service users continued to retain possession of a high volume of items. The interplay of the participant's thoughts and experiences evidenced a range of reasons for these phenomena:

"I suppose it's something that that they would probably think isn't their responsibility as much and it's something they wouldn't remember to do it's probably more convenient to have the equipment there in case anything ...changes with them longer term so they might just think it's something that they keep ... through choice" (Pat).

Similarly, the 'just in case' phenomena was further supported by Mel:

"I think they do just take it off store it away somewhere whether that's because they think oh I might need it later on in life and if it's here I can get one cause I think sometimes people patients maybe have the perception that to get equipment can be really difficult or they've got to pay for it or they've got to become really unwell before we give it to them which isn't always the case".

Clearly, the implications of service users hoarding equipment on resources and stock levels are potentially significant. Firstly, lower stock levels will impact on the timeliness of both hospital and other places of discharge (such as intermediate or residential units). Secondly, as discussed in Section 5.3.2.1, there is a resounding impact on the physical and emotional well-being of the service user and the therapy staff. Ironically, Mel and others referred directly to the concept of over prescription which further contributes to the overall lack of or availability of stock:

"I do find like on a whole people can be a bit ... we just should provide it because ... they might need it in the future I think some people can provide a bit too much like or the patient has said to them I think this will be useful for me like a bed lever they can they can then transfer independently but the patients are thinking ooh that'll be useful and I think people can be a bit too equipment happy and provide a bit too much too soon cause then I think that tends that does take away from their if they're pulling themselves out of bed they're not using all their muscles they need and then they're gonna loose it more quickly so I do find that can be a bit of a like we can be a bit equipment happy".

Mel's perception of occupational therapy colleagues as being "equipment happy" further reiterated the link between professional identity and competency with the provision of ADL equipment. There was the sense that to be seen as issuing 'too much' equipment without a clear rationale or link to clinical reasoning failed to promote the profession of occupational therapy but rather echoed the perception 'people have' of occupational therapists as equipment providers.

In addition, Mel drew further attention to the increase in dependency equipment can cause. Whilst acknowledging there was a 'quick fix' perception of equipment provision Bobby was firm in their opinion that at the time of provision the equipment would have been needed. However, there was an emphasis on both users and providers to take greater responsibility, supported by a robust reviewing system, to ensure equipment which was no longer in use was returned or collected:

"I think you know experience in pre in previous roles I think equipment has been put in but like I said this it's not necessarily just the service or the community I think it's the provision of the piece of equipment and err the education I think as we develop as services we're learning more about diseases and treatments and about enabling people you can never stop learning about it that I feel now that we need to box more clever in our equipment provision and sometimes it has seemed or perceived as being a quick fix but at that time it's what that patient needed but it's about that patient coming back it's not just the responsibility of the provider it's also the responsibility of the person excepting the piece of equipment to say do I really need this now you know and you know is it a short term loan is it a long term loan and it still needs to be reviewed and it's having that system in place so I think it's more of a process than any service or the patient" (Bobby).

Furthermore, as indicated by Bobby, equipment retained by service users for the future may then be inappropriate to their needs or become unsafe to use. As such the need to determine service user's ability to recognise when equipment was no longer required and how to return it was important:

"we've had two instances where one person has been given err a bath board and it's split so to keep equipment well and in good shape is to ensure if somebodies not using it it's taken away because if they use it in two years' time and it breaks where do we stand then we didn't know they hadn't used it for two years and it's sat in the cupboard and were they using it right after two years so we need to get smarter in how we inform and it is about educating the person and making sure if they're not able to understand that that there is a system in place".

The implication here is the potential risk to the service users and the organisation if the process of returning equipment is found to be inadequate.

For several participants, a sense of entitlement was offered as an explanation for excessive prescription and equipment retention. Irrelevant of the mechanism of provision, many occupational therapists had observed the consequences of equipment which was not returned:

"people like to like hang their clothes on kitchen trolleys or free standing toilet frames cause they don't need them even if they've got them they don't act they never wanted them [...] I suppose they agree with it because the they feel like they should have it but they don't want it so they are saying yes I'll have it and then never use it" (Kris).

Whereas Mel and to some degree Sam, discussed how it was not unusual for everyday items to become integrated into our environments. As such, subconsciously we (as individuals) all inadvertently use items to store or hang things on:

"I think people just they're used to having it there and they're like that they just they like you say they find different uses for it don't they like that's your clothes horse now and you just sling it over I think they just ... everyone has that chair in their room that they chuck things on and I think that just becomes that for them sometimes it's just it's always been there and they just don't and sometimes I think they don't realise that because it's been in their home it can still come back because it can be cleaned so I think it's almost like it's just habit to do that or it's always been there now for as long as they can think so they just don't think about it" (Mel).

Alternatively, being unafraid to comment on equipment which was being used for other purposes and removing it was as equally important to help maintain stock and reduce the burden on resources:

"you would occasionally go and do an assessment at somebodies house and there would there might be a kitchen trolley that were used as a plant stand or [smiling and J laughing] an but it I was I was quite comfortable to say you know if you're not if you're not really using that I could take it back for you and make it sound like I was doing them a favour" (Sam).

Glen was sad regarding the lack of advice given to service users who may choose to privately purchase equipment. This was particularly pertinent for those who lack the same financial opportunities as others, especially when the equipment is of no practical use to them.

"I think it's sad that people don't get the advice that they really could have and will potentially buy things that aren't particularly useful to them or that don't help as much as they could do [...] and you know the classic example is the private purchase [...] chair [...] they'll go out and buy a [...] chair and you just think oohh okay so actually you're sitting in a really horrendous position and actually you're likely if you sit in that for very much longer likely to cause yourself disability even if you didn't have it before [laughs] and actually that must be really difficult because your seats sort of 18 inches wide and you're only 14 inches wide [...] so I think it's a shame that people don't get you know it's great if people if you want people to self-purchase that's fine but it'd be still nice if they got the right advice so they got the right thing for them and how many times have you been out to somebody and they'll say yeah I bought that myself or I bought myself this or I bought myself that but actually I can't really use it ... and that's that seems a shame for people especially for some our clients who perhaps have limited means" (Glen).

The additional implication here is the ease of access of equipment through the high street or online which compounds service users' ability to source equipment which may then be unsuitable. Equally, this ties into the points made in Chapter 4 surrounding the participants threat of the loss of their professional identity as the opportunities to source equipment broadens. Or, perhaps it is the knowledge that as occupational therapists we do it better than everyone else because we are thinking about more than the equipment, we are considering amongst others the person, their occupations and the environment.

### 5.3.2.4 Being safe

According to Ricky, professional conflict occurs when attempting to balance independence with service user's psychological fears such as falling. Despite acknowledging that excessive equipment provision could result in increased falls Ricky admitted to providing equipment as a compromise to allay service user and family concerns. Here Ricky recalled a specific experience of providing a commode to a service user, who if the criteria was strictly followed would not be eligible:

"the equipment was provided ... some equipment was provided that wasn't necessarily needed [...] confidence patient it was a commode she wanted one by her bed ... but she was independent with bed transfers she was independent with toilet transfers she was mobilising a fair distance on the ward further than what her actual toilet was at home but her concerns were in the night she wanted it close by so she weren't having to walk far so I did that even though again it was I could justify why she didn't need one ... that it was just purely for the patient to try and reduce that anxiety of using the toilet in the night".

The perception of anxiety and fear experienced by service users was evident in the above excerpt where the basis of equipment provision was based on want rather than clinical need. There was evidence of differing types of fear. One related to feelings of personal safety, whilst others feared that returned equipment may not be provided in the future should it be required. The complexity of a truly holistic assessment was also highlighted. The concept of service user's fear and surrounding misconceptions were highlighted in the following excerpt:

"I think sometimes it's like a ... state of mind so if it's there they feel like and they they've got a bit more support even if they don't use it it's like a bit of err like one day they might not be able to and it's like which if they weren't if they were variable we wouldn't take it away [laughs] that's but I mean like they might think that they might need it like down the line whereas we could always give it them back or assess then for it again so it doesn't have to permanently taken away or given" (Vic). This highlighted several reasons why service users may safeguard their equipment. Whilst several of the occupational therapists accepted equipment was provided as a safety net, including Vic, "*I think if there's a slight need they might give it them* ... *sometimes it's for peace of mind of the patient or the family*" an additional factor was one of time:

"on the surgical wards and orthopaedic wards where I've worked in the hospital it's more about discharge planning as soon as you're going as soon as you meet the patient they're wanting them to be out so it's looking at personal care ... domestic activities so in the kitchen assessing if they can make a cup of tea or toast and supplying and assessing any equipment that they need delivering it ordering it making sure that their home is safe for the equipment to be fitted or wheeled around" (Vic).

At times, Mel focussed on service users' overall safety during their interview when outlining how they felt it sometimes necessary to observe equipment use within the home environment. Mel was particularly uncomfortable with how service users use, or in some cases do not use, equipment in their absence:

"you think about how they're gonna use it first and can they use it safely [...] I won't give anyone equipment if they're not gonna be able to be safe using it which is why we practice here and we can practice it in their home so I always think about are they gonna use it safely when they go home are they gonna continue to use it safely and how we recommend them to use it just like a kind of like a static commode make sure that it's against a wall are they gonna continue to do that at home or are they gonna get someone to move it just little things like that".

Whether equipment was in active use or simply to hand for a just-in-case moment the conflict of 'doing the right thing' was a constant professional challenge, "*it's not quite black and white all the time is it*" (Ricky).

# 5.4.3 Super-ordinate Theme: Moving into the future

The final super-ordinate theme in this chapter highlights participant's perceptions of the future of occupational therapy practice and ADL equipment. Both positive and negative viewpoints are considered.

### 5.4.3.1 Changing landscapes

The landscape of equipment provision is changing, as is the perception of the occupational therapy role, for example: *"they'll always be a role for equipment but* 

whether that's an OT role" (Glen). The widely acknowledged decreased exclusivity of equipment which can now be sourced privately via a widening range of outlets supports the belief that it (equipment) no longer 'belongs' to occupational therapy practice. Despite this, to support service users with their choices and prevent unsuitable purchases, participants highlighted the ongoing need for continued "proper assessment' (Bobby) in suitable environments. Future occupational therapy assessments may take the form of "consultation and case management" (Bobby), be aligned with roles within equipment-based companies or with private equipment providers (Glen). While Glen suggested occupational therapists working for equipmentbased companies offers an increased level of consumer confidence s/he did not discuss how the ethos of occupational therapists fit within a profit-based business model. Whereas Jo simply stated, "I hope it'll stay the same". This constancy allays therapist's fears of service users being able to access equipment they do not understand and the resulting consequences. Additionally, service users increased knowledge and understanding of their diagnosis and how it can be managed was recognised:

"I'm hoping it doesn't go that way cause I think that could be quite dangerous for people who are disabled to go into a stores and say but I think there are definitely more expert patients now" (Jo).

Here the participant circuitously suggests service users increased awareness must be taken into consideration during the assessment and any decision-making processes. Alternatively, the reduced volume of face-to-face contact between occupational therapists and service users was raised as a current and future concern; one which is feared to increase over time. The focus on facilitating timely discharges rather than quality of interventions is contra indicatory to the core premise of occupational therapy practice:

"time restraint is a big thing the amount of time one on one contact we have with patients seems to be getting smaller and smaller and the amount of times you get to see a patient is greatly reduced [...] we don't get to review patients as thoroughly as we would like to progress them as much as we could ... I suppose it's a bit like a discharge facilitation service so it's making sure they are able to get home quickly and safely which I suppose is a bit opposite to what OT is in a participating in a meaningful activities and it's ... let's get you up and running as quick as possible and ... have some equipment to support you but that's not what we're here to do to get them back and back to where they want to be as much as possible and doing the things they want to do or an alternative but safely" (Kris).

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Inadvertently, the emphasis on timely discharges which inevitably results in higher levels of equipment provision reinforces the misplaced perception of occupational therapists' primary role as 'being about equipment provision'. In effect, the emphasis on discharge planning fuels others perception of the occupational therapists identity as one which is focused on equipment.

The issue of future funding was perceived as a barrier by several participants. Mel observed this as particularly challenging when referring specifically to some Trusts which, they believed, only provided equipment on a short-term basis:

"whether funding will come in to it I don't know you never know with funding and whether that'll be a thing and whether I don't know if some Trusts already do it I think they do whether I know we don't here I don't know whether err we say to the patient this is yours for x amount of time I believe there are some Trusts that do say that okay we're gonna give you a commode but you can only have that for like four weeks because I think that's gonna be a barrier because that's that I see quite like scary cause if they need a commode and they're not gonna get better why can't they have that commode for longer".

Equally, Vic foresaw working with an increased number of bariatric service users and an aging population would require an exponential growth in the number of community based occupational therapists:

"V: working more with bariatric people and more with older people so I think that equipment use is gonna increase and gonna be about trying to keep people at home rather than in social care beds ..... the future of OT ... ... so there might be a surge of like OTs in the community

*R* how do you think that's gonna fit in terms of equipment as it is at the moment then

V: what with the same stock [laughs] it's gonna put extra strain on the equipment service and the budget and it might make it harder and to like get equipment so maybe more reasoning on the equipment request form why a patient needs it more justification maybe for a certain amount of time they might be allowed it and then like review it so that it's not just lost in the community so they're gonna have to order like stronger and bigger equipment which is probably more expensive ..... probably being more part of like emergency teams to try and reduce people coming into hospital and probably more equipment again".

Here, Vic highlighted how already stretched resources would be further compromised which though not stated would ultimately place additional strain on processes such as the equipment panel. The consequences would be longer waiting lists, a reduced range of items available through statutory provision and added pressure on therapists when justifying equipment. The latter would include a personal sense of professional pressure alongside increased pressure from the organisation not to provide and the service user to source and provide their own equipment.

## 5.4.3.2 Feeling threatened

Bobby celebrated the notion of other professions replicating elements of occupational therapy into their own clinical practices. They viewed this as a positive reflection of occupational therapy rather than a direct threat to its long-term existence:

"OTs I think is people are thinking oh there's no need because they feel like a lot of other professions are doing a lot of what OTs does I's like no that's OT in the past silently improving peoples acknowledgment of enablement of people and it's just we want to be proud of ourselves".

Similarly, Bobby expounded the view of shared terminology which indicates a shared rather than conflicting approach to treatment:

"I think we've got many skills and I don't think feeling threatened by other professions that they're using terminology that we would use it's we should take that as a positive in the fact that people are thinking along the same lines as we do regarding the patient".

Furthermore, Bobby did not believe occupational therapists should be the exclusive provider of equipment and regarded equipment as a small area of clinical practice. Bobby was equally unconcerned with who provided it:

"I think equipment's always gonna be in our life because it's part of supporting somebody and enabling somebody to go forward whether we prescribe it doesn't really matter but I think we need to suggest it and we need to have an element of knowing what is available and we still need to try equipment too cause it is part of what we do and enable".

This indicates a continued long-term relationship between occupational therapy practice and equipment, but one which is not at the forefront of practice. This backstage positioning should therefore allow occupational therapists to concentrate on and develop other areas of practice: "*I think it might lead to different directions and unusual directions*" (Bobby).

In contrast, Glen was dismayed at the potential loss of the occupational therapy role:

"you know I'm always hearing on the television and on the radio these fantastic new things that are people are doing like using gardening as a therapy because actually doing an activity is really good for somebody I'm oh my goodness or I was listening to something the other day where there was a some physios using oh like a virtual reality program to do something but they were like oh my we can get them to do an activity and I'm just thinking well this is what we've been doing since time immemorial as OTs and we don't shout about it and the college of OT is just doesn't seem to you never hear from them you never hear about them and I just thought maybe just everything that everything to me that set felt core as an OT other people seem to be picking up and doing and I just wonder if maybe there isn't a role for OT anymore maybe that's and I suddenly thought maybe I just have to accept instead of getting angry like I've been doing for a long time and shouting at the telly or the radio maybe I just need to accept maybe ... there isn't really a role anymore and it will just get absorbed into something else".

Glen's bewilderment of other professions increasing realisation of the benefits of activity and the lack of support from professional bodies shone through. Furthermore, Glen was frustrated and despondent regarding the past enforced redundancy of the occupational therapy "*skill set*". Glen was disillusioned by the commendation and tolerance other professions now receive when they exult the benefits of activity and occupation within their own clinical practice:

"we've should have as OTs a wonderful skill set that is never fully utilised I see at our Trust now they've got specialist dementia nurses and I went to our dementia training that's put on by one of the specialist nurses and I sat there and at the end of it she was asking for feedback and I said that I just feel really really sad cause what you're talking about is what we were doing in OT over 20 years ago and you've stopped us doing it because we were delaying discharges etc etc and now you're saying oohh we need to do this and it's just yeah ... [...] I feel depressed about it really [...] and I'm a really passionate OT".

# 5.4 Reflexive thoughts and ideas

Similarly, to the content of Sections 4.4, I found Smith et al's (2009) six step approach a useful guide when conducting the analysis process. I used the knowledge I had gained from analysing the clinical leader data to inform my approach for this sub-group. This did not however make the process easier overall. For example, due to the richness of the data collected during the interviews selecting the key issues arising during the analysis process remained challenging. As such, selecting excerpts which effectively demonstrated the experiences of the participants in a meaningful way was challenging, as was the process of reconfiguring and refining. Equally the sense of responsibility to ensure the participant's voice was represented was not lessened.

As with the previous analysis and presentation of the findings in Chapter 4, I again underestimated the time involved in the analysis process. I believe the time spent analysing the data signifies an ongoing attention to detail and commitment to ensuring the participant's voice was heard. I remained aware of my interaction with the participants and my attempts to not lead responses. However, it is clear in some instances that my attempt to achieve this resulted in protracted questions.

As found in Chapter 4, the voice of the participants in this sub-group captured their experiences of equipment assessment and provision as occupational therapists. The perceptions of the participants in this sub-group were found to reflect the experiences of the clinical leaders in the previous chapter. This may not be unexpected as all the participants in the two sub-groups were practicing occupational therapists. The content of the two chapters accounts for the similarity of the super-ordinate themes and sub-themes which developed during the analysis process. They may also be reflective of the interview questions which were not dissimilar in places. Additional questions were asked, or prompts offered dependent on the participant's responses. As with the previous chapter, the findings have highlighted the intricacies of ADL equipment from the perception of occupational therapy practice.

#### 5.5 Summary

This chapter presents the findings of the ten occupational therapists who consented to be interviewed within this sub-group. All ten of the participants held a clinical caseload. Not all the participants were responsible for junior occupational therapists, though many worked with technical instructors. Participant extracts were selected to demonstrate the participant's experiences and the researcher's interpretation of these.

Similarly, to the previous chapter, the concept of 'identity' was woven through the findings. The occupational therapists were as concerned with their own professional identity, the perception others have of the occupational therapy profession and that of the service users. The emotive topic of service user identity signified the importance of equipment whilst also highlighting the need for a subtle considered approach to its introduction and use. Several issues were identified by the participants regarding the

availability of equipment, namely funding and resources and existing processes. Whilst there was a sense of positivity for the future of occupational therapy, equally, there was the impression of foreboding and melancholy from others.

Chapter 6 presents the findings of the final sub-group – the service users before Chapter 7 considers and compares the findings of all three sub-groups.

#### Chapter 6: Findings – Service Users

As with the previous Chapter (5) which presented the occupational therapist sub-group findings, Chapter 6 begins with a summary of the participants' backgrounds. Then follows a précis of my perceptions of the interviews and participants engagement. The chapter then explores topics which arose during the data analysis process using purposefully selected excerpts to support the findings. Each super-ordinate theme is introduced prior to the related sub-themes. My overall interpretation of the findings for this sub-group are then summarised.

As with the previous two chapters, all the participants were assigned a pseudonym to maintain anonymity. However, in contrast to the clinical leader and occupational therapist sub-groups the need to use 's/he' was considered unnecessary due to the wider pool of participants within this sub-group. Furthermore, many of the participants referred to their wives and husbands, him or her, and she or he accordingly. Equally, it was agreed by the main researcher and the supervision team that altering participants words would be inappropriate.

#### 6.1 Participants

Overall, 12 service users with recent experience of occupational therapy input expressed an interest in being interviewed of which seven proceeded to consent to interview. Two were members of the local support group as highlighted in Section 3.3.1. The remaining five participants were recruited according to the process outlined in Section 3.3.3.3. Of the five participants who did not go on to consent to interview four withdrew their interest and one could not be contacted. In line with the right to withdraw (Section 3.3.3.3) the participants were not obliged to provide a reason for their decision. The length of the interviews varied between 24 and 150 minutes. Of these, four were conducted within a 60 minute time frame and one 120 minutes.

The participants were not asked directly for their ages during the interviews, however five offered without prompt. As such, the youngest participant was 35 years and the oldest 87 years. Three participants were aged 57, 62 and 77 years, with the remaining two estimated to be in their mid to late 70s. Two participants were female. Prior to the commencement of the interviews, two participants requested family members remained present during their interviews. As such, a spouse and son were present during one interview and a spouse during another. All those present at the interviews contributed their experiences following clear invites by the respective interviewee. While it may be

preferable to interview participants alone (Smith et al 2009), the presence of third parties such as family or carers was discussed and considered permissible during the REC ethical application process.

All the participants within this sub-group were asked specifically to "tell me a little bit about your condition or conditions". This prompted a list of various diagnosis or comorbidities all of which involved long term conditions which were neurological, musculoskeletal, systemic, cardio/respiratory or sensory in nature. Three of the participants highlighted long term health issues affecting their spouses, similarly these were neurological, cognitive or orthopaedic in origin.

Though not asked during the interviews, five of the participants volunteered their employment status or history. None of the participants were in paid employment at the time of their interviews. Five had worked previously though were now retired with four reaching retirement age and one who retired early for medical reasons. Three of the five had been involved in the motor industry and one in engineering. The work history of the remaining two participants is unknown.

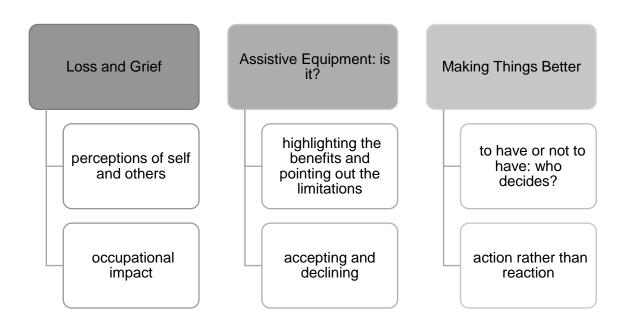
The participants were in receipt of a wide range of ADL equipment, some of which had been provided by statutory services, others privately purchased. Equipment for personal care [for providing access to the toilet and or washing and dressing], mobility, kitchen activities, access and egress and negotiating stairs were all listed.

#### 6.2 Interviews

All of the interviews took place in the participant's homes at a time convenient to them. Access to drinks and other facilities was led by the participants and unrestricted by the interviewer. Similar to that of the occupational therapists' narratives in the previous chapter (5), I was aware of differences in the narratives offered by the participants. As reflected in the length of the interviews one participant in particular appeared more pragmatic and less reflective whereas others were more expressive and keen to share their experiences in more detail. For the more pragmatic responses attempts to expand the experiences were at times unsuccessful and which accounts for the use of questions which in hindsight may have been leading. However, where it became clear the participant was hesitant or unwilling to expand their responses the subject was not explored further, and the interview was moved on. In contrast, two participants tended to go off at tangents in line with their thought processes. This reflects the sudden stop in their excerpts particularly when they do not return to the original experience. However, these detours led to other insights about them and their experiences. All the participants injected a sense of their humour into the responses they gave. While the use of humour may be indicative of the participant's characters, it may also have been used to dampen, belie or conceal true emotions and feelings. Within their interview Robin referred to 'suicide'. Following the interview, the researcher returned to this statement whereby Robin expressed and reiterated no active feelings of self-harm to any degree or level. Robin was aware of the support and services available should this change.

## 6.3 Super-ordinate Themes and Sub-themes

As presented in Figure 6.1, three super-ordinate themes and six sub-themes arose during the data analysis and writing process. As with the previous two chapters each super-ordinate theme is introduced before the associated sub-themes are presented and supported by transcript extracts.



### Figure 6.1: Final set of super-ordinate themes and sub-themes – service users

# 6.3.1 Super-ordinate Theme – Loss and Grief

Grief is a naturally occurring emotional, sometimes physical response to the loss of someone or something. Responses are personal and subjective which alongside physical and emotional factors also includes behavioural and cognitive components (Watson et al 2005, Cooper 2006). All of the participants within this sub-group appeared to be experiencing or have experienced loss and thereby grief due to their

diagnoses and the impact of this/these on theirs and others lives. Associated feelings included depression, anger and sadness. With this in mind, the following superordinate theme explored the participant's perspective of how their diagnoses has affected them and others. The impact on health and well-being, specifically physical, psychological, and social factors are discussed. Similarly, as with the previous two chapters the concept of 'identity' is interwoven throughout.

### 6.3.1.1 Perceptions of self and others

All seven participants or the family members present offered an account or insight into the story behind their diagnoses. Underlying this was an overall sense of loss. For example, Mattie recalled how different things used to be:

*"it definitely does have a big impact you don't realise you know you don't realise really until you've got something how you take things for granted I think don't you".* 

Psychologically Mattie's sense of loss was later compounded by one of despair at the unpredictability of her condition:

"I do think you get really down with it because I think it's you know ... I think the thing is as well is it's a condition that changes so much every day yeah you've got all these aches and pains and stiffness and that but then it seems to throw just something else at you and something else it's like I'd never had a problem with my eyes at all and in March I think it'd be all of a sudden I started with this my eyes going dry and then my nose and my mouth and then now that's every night and I get horrendous pains through my eyes and into my head and so yeah I think it does get you down".

Mattie described how the unrelenting nature of her condition led to feelings of low mood implying a link to depression which when combined with new symptoms led to a cycling down of well-being. Equally, Robin vividly described his symptoms as "*a terrible pain it's a horrible pain that I suffer with its stinging aching burning fatigue*". These emotive words presented a 'picture' which whilst cannot be seen can be imagined by the reader. Later in their interview Robin presented an image of pure hopelessness mirroring Mattie's own sense of despair:

"some days I'd be honest with you I sometimes think and I've told me doctor this I've said to him sometimes I go to bed and I lay there and I think oh perhaps if I could just go to sleep and don't wake up anymore that'd be so fine ... because I do get like that I get where I'm not suicidal I'm not gonna go and hang meself or commit suicide but I just feel that if I could go into a deep sleep and never know nothing again that would be fine for me because ... it's not just the face I've gotta face the day the next day that doesn't bother me it's the bloody pain it's the pain and the agony that I'm going through" (Robin).

These excerpts evoke an overall sense of loss which incorporated Mattie and Robin's physical, psychological and emotional health and well-being. The probable impact on their previous lifestyles was palpable. For example, prior to the onset of symptoms and diagnosis, Robin referred to having lived a 'normal life'. Robin described his business and lifestyle with pride, affection and in some detail whereas now after living with the condition for several years he stated, "everything just seems too much of ... too much of a ... a hassle for me" or "I just can't be arsed". This reiterated Robin's sense of hopelessness and despair: a perpetuating circle. Robin's emotions were multifaceted and conflicting. For example, on one hand he openly admitted to feelings of depression, whereas on the other he evoked a strength of character to carry on regardless:

"you get up and you feel absolutely crap well that's how I feel everyday ... but ... I well you've just gotta blunder on I just blunder on and think well you know tomorrow's another day I've some't might come up some't might not".

During his interview Robin expressed frustration and anger toward past friends and acquaintances who he perceived did not understand his condition or its impact. Equally, Robin's words indicated his friends had observed a change in his personality and character. The experience and feelings expressed by Robin highlighted a sense of loss from both sides, from Robin and friends, which underlies a change in identity from one which was outgoing to one of an acquired passivity:

"and then it's like as like I said going back to my friends and that they all oh you're not the same person since you've had this problem you know you don't come out with us no more you don't come round to visit us you don't do this you don't do that you're not very you're not very good hospitality and all the rest of it and I'm like you're joking ..." (Robin).

Conversely, Robin was clearly mindful of protecting the feelings of others, particularly his mother:

"you probably know more about me than me mother knows I don't tell me mother all this cause it'd just worry her to death it would kill her anyway ... you know I just say oh yeah I'm alright mum oh I'm bouncing on springs today yeah I'm alright and I'm not I'm in absolutely excruciating pain ... but I don't believe in ... torturing other people and causing other people stress ... and grief over my health conditions it's a health condition it's hey man you've gotta get on with it".

Again, Robin's turn of phrase was highly descriptive and painted a vivid picture for the reader. Whilst the phrase "*bouncing on springs*" was a probable exaggeration of the words he would use it is likely that Robin played down his feelings so as not to burden others. Robin took ownership of his condition so as not to affect those he cared for. Equally, Robin's apparent jocularity and use of wit probably misrepresented his true feelings and emotions. In reality, he may miss the opportunity to be open to family and friends and share with them his experiences and emotions. In essence, Robin was aware of how his identity had altered in response to his diagnosis, equally that friends perceived him differently and his attempt to hide the new Robin from family. Toward the end of his interview Robin compared himself to others and whilst appearing pragmatic also wished for some magic:

"R: I just take every day as it is and I think well you know tomorrows promised to no one but we're still here that's the main thing ... I sometimes wish there was a magic wand you could wave and say oh well tomorrow morning you will be better ... my wish is your command and it happen but it

Researcher: one puff and it's done R: yeah but it just doesn't happen does it Researcher: no R: and there's I have also appreciate there's also people in a hell of lot worse state than I am you know people that suffer with other chronic fatigues and health issues and that there's worse I've seen people worse than myself ...".

This excerpt offered an insight into Robin's mixed emotions. On one hand he expressed a sense of realism whereas there was also evidence of frustration and hopelessness that his life was unlikely to improve.

Similarly, to Robin, Denny provided a vivid picture of the personal effects of her diagnosis and how she perceived it affected her family. The psychological impact of Robin's limitations evoked anxiety and unease, particularly for her children:

"I even have my little five year old crying at the door for mummy to get out of bed because mummy can't get out of bed some days [...] it's a big impact it does it drags me down".

Here Denny was more concerned about the welfare of her children compared to her own well-being. In addition, Denny felt responsible for the position her diagnosis placed the children in and the guilt brought on by the physical support she needed. Denny was as equally humiliated by the indignity of being supported by her older child alongside that she perceived was experienced by the child themselves. In essence, both Denny and her son experienced the loss of dignity associated with the same task but from their own perspectives. However, in Denny this knowledge also summoned a sense of pride in her son:

"my eldest one helps out a hell of a lot [...] he's actually used to seizures if he sees me having one he knows exactly what to do so if my husband has to pop out to take the kids to school or take em to a club he stays with me all the time so he's like my second carer basically ... bless him [...] awful it's mortifying when you have to have your teen well pre-teen actually in the bathroom with you because you're scared you're gonna have a seizure in the bath or fall off your bath seat it's awful that no child should do that ever but unfortunately I have to rely on him as well as my husband which is it is demeaning it really is demeaning a child shouldn't see you at that age with nothing on so it is very very demeaning so".

Whilst having previously described her son as a 'pre-teenager', in this account of her experiences Denny referred to him as a child which may subconsciously corroborate feelings of guilt by highlighting a greater sense of youthfulness and vulnerability. Denny's experiences also hinted at a change in roles, with her son taking responsibility for her needs rather than the opposite way as would be expected in a mother son relationship. Billy was equally conscious of the loss of independence and the impact of this on his wife:

"I can't go to the toilet without she's there to help me with the buttons err sometimes I don't quite make it in time which is very embarrassing generally getting dressed I can't not on my own she has to help with buttons and things socks getting ready for bed [indecipherable] and if we're going out anywhere she has to make sure she sits next to me err in the restaurant because one of the problems with Parkinson's is swallowing".

Here Billy's inability to access the toilet in a timely manner highlighted his loss of independence and his sense of dignity in relation to ADL activities. Billy identified a

number of tasks he was unable to complete without his wife's assistance. Later, he succinctly summed up his wife's role and what she means to him, *"she's excellent worth more than any of these aids"*. The fondness with which Billy referred to his wife and the sacrifices he perceived she had made for him gave a sense that compared to the equipment he considered her as 'priceless'.

For Fran, despite an understanding of his diagnoses, there was a sense that prior to his interview he had not fully considered his life and ability now compared to his past. As such he emitted a sense of loss:

"F: I didn't realise it that I now do that I'm very slow aren't I I can do things eventually [...] oh I think it has made a big difference to myself
R: okay in what way
F: err I can't do the things that I used to do
R: mmm such as
F: virtually anything I mean it isn't that long ago that I was able to play bowls still wasn't it
Son: mmm
F: err and err you know take part in those sort of activities".

This sub-theme highlighted the participant's perceptions of their diagnoses and the impact on them and those close to them. It particularly demonstrated factors relayed to emotion and dignity. The following Section (6.3.1.2) explores the impact of diagnoses on the participant's occupations.

### 6.3.1.2 Occupational impact

For all the participants' their diagnoses had a resounding impact on their 'everyday' activities and occupations whether personal, domestic, social or leisure. For example, Mattie recalled past holidays and visits to family when 'doing things' would be second nature whereas now she, her husband, and family are restricted to the humdrum of *"day to day"* activities. Throughout her interview, Mattie spoke intensely about her sense of pride in the house and the time she would spend cleaning and tidying. Whereas here, Mattie described how her diagnosis impacted on her role of being a mother and 'keeping house' to the standard she was used to and how both of these generated melancholic feelings:

"holiday wise we've not done what we normally do just day to day living I mean I'd just get in the car and go over to my daughters one's over at [place] and the other one's at [place] and I'd just not think you know not think twice and it's even your housework it does get me down cause I can't keep on top it like I used to do sort of thing I say it's a quick flick round when you feel okay and hoovering I really struggle because my backs starts after a couple of minutes ironing I do so it does impact on everything I think" (Mattie).

However, as Mattie highlighted in the above excerpt, the lives of others were as equally affected, often in ways which may not be fully appreciated. For example, whilst Mattie was concerned with the reduced contact, she had with her daughters she perceived one daughter lacked some understanding of her diagnosis and the barrier this raised in terms of completing everyday activities:

"I know my daughter one of my daughters doesn't quite get it cause we used to go up sort of like to the ... outlet a lot up at York Fulford".

In the first excerpt Mattie conveyed a sense of guilt in her inability to visit or spend time with her family as frequently as before. The second excerpt demonstrated Mattie's sadness at the thought of her daughter's lack of understanding. In contrast Billy papered over his determination to continue with one specific activity with humour:

"B: I go every Monday morning at 9:00 o'clock [...] good start to the week [...] yeah Parkinson's it's too easy to sit and do nothing I don't like having nothing to do cause I never know when I've finished [...] yes my average is on a downward spiral but I don't mind I don't mind that [...] yes the I bowl with a friend and if I win a game fantastic a disabled person's won [R laughs] so I can't lose can I [B laughs] cause if I lose a game well he's disabled [both laugh]

R: you've obviously still got a sense of humour as well

B: yep well it takes a lot to get me down".

Billy recognised how his diagnosis had the potential to cause him to sit and do nothing alongside how it affected him overtime. Despite this Billy seemed determined to and stressed the importance of remaining active. Whereas for others such as Denny, the ability to continue was deemed impossible:

"just constant pain I mean I'm actually in pain sat just doing nothing so it's like just trying to get up and go places is really hard I mean normally years ago we used to take the kids out you know every holiday we'd go out every day to do something I can't do that anymore it's just awful unfortunately" (Denny). Parallel to praising and admonishing the equipment issued to him, Robin summed up the overall despair he felt:

"I'm probably being a bit silly saying this but ... I would have thought that ... the part the bits that they brought to the house is the last thing I need it's the help with the pain I need ... I assume that this is supposed to help me with the pain cause I've got a thing in me bed to pull me sen in and out of the bed but I've managed ... talking fifteen the fifteen years I've managed with it I've struggled it makes it does make life a little bit easier same as the bath slat it makes life a little bit easier but if you said to me ... what would you prefer I can tell you straight away what I'd prefer I would prefer ...".

Robin later described their perception of simpler solutions such as exercise or a change in diet to combat his diagnosis. There was the sense here that no amount of equipment would help, he simply would prefer the pain to stop. This further highlighted Robin's sense of hopelessness and despair. Mattie's thoughts followed a similar vein:

"they have been a real blessing really all together but what I need now is just some appliance that just does all the cleaning and the hoovering and [laughing] that's it the thing out of all is you look at all these and you think yeah they're a godsend and they really really do help but then you just think I'd love one day just not to need any of em and just to be able to get on with it you know".

Like Robin, Mattie indicated occupational change due to her diagnosis whilst praising the impact of ADL equipment stressed it does not compare to being well or pain free. In essence, equipment did not truly compensate for the challenges they faced. The tangible impact of equipment on the emotional well-being and overall quality of life of the participants was evident. Fran and his wife repeatedly expressed their desire to remain in their property despite their failing health and recognition of their declining abilities:

*"F: we can't err can't get up and down wouldn't be able to get up and down without it* 

*R*: so if you weren't able to get up and down without it then what kind of effect do you think that'd have on you

F: well I I'd be here all the time

Son: or we'd apply for a downstairs flat that's the only other thing we could do

*F:* yeah but we like an upstairs flat because it gives you a better view I mean it's a beautiful view here ... and err no I wouldn't want to go into a downstairs flat [...] well it's lovely it is we couldn't wish for anything better

Wife: I don't want to move I love sitting here watching the world go by".

And later:

"F: I think it is important that ... people stay ... as long as possible in the location that they're at already at ... I can't stress that enough or R: why do you think that's important Wife: because we like living here Son: it's your home isn't it F: it is Wife: yes it's our home F: yeah and to move people away it ... its wrong Son: and we've even talked about you getting you downstairs and F: we have we've talked about all sorts of things Son: but you don't want to do you *F*: we've no intention of doing it Wife: no intention of moving Son: no you want to stay here F: yeah Wife: we love being here.

Both Fran and his wife were emphatic about remaining in the home they had resided in for just over 20 years. Without the stairlift, Fran would be unable to negotiate the stairs which would result in his being unable to access his local or wider community. He was unperturbed by this, with a perception that his life would be affected by things other than the lack of equipment. For Fran life was about the whole package, his environment, the equipment and who he was with. Similarly, Mattie recognised the difference equipment combined with other services had made to her mother-in-law:

"because of what she's got she can stay where she is and I mean she's been adamant for a good few years that you know she keeps saying I just don't want to go in a home and we keep saying you don't have to do because you've got all this provided and now she's got carers just to sort her tablets out morning and night and she has a lady that comes in and cleans for her and stuff and so it's given her that she can stay at home ....".

Due in part to the ADL equipment provided, Mattie's mother in-in-law was able to remain in the environment of her choice, was maintaining a good level of independence which would have a positive impact on her over-all health and well-being. The motherin-law was able to retain the roles important to her and by association her identity. Mattie later compared the cost of equipment and additional services with the financial implications of placing individuals into long term care, the latter of which she considered the most expensive. As with Fran and his family, Mattie was convinced of the benefits of remaining in your own home and how this could be achieved through the provision of equipment:

"one of [her] brothers has kept saying oh well I think she'd be better off in a home we said no she's got everything it's given her independence ... and you know she's had things added to I mean as I say she's started off with like the toilet seat and the walker and things and then she's had like all these rails put on then she's had the rails put for outside and everything and so as I suppose as she's deteriorated a bit something else has been added to it and she's as happy as a lark cause she's still got her independence ... which is absolutely brilliant you know so I mean yeah and there's nothing better than that because I think ... you know people are just meant to be in their own home as long as they can don't they [...] I've still got me pride she says and I can still get me shower meself well if she didn't have that equipment she couldn't do it".

Simply put, for Mattie's mother-in-law the equipment enabled her to remain at home even while her physical ability deteriorated. As above, the mother-in-law was able to maintain her roles, dignity and her identity. This demonstrated the versatility of equipment to be adapted to accommodate change in an individual's ability and capabilities. With regret, Mattie then recalled her mother's experience, and the difference equipment could have made to the quality of her (mother's) life:

"me mum died gosh twenty years ago nearly and it was only I think then you didn't seem to get have as much with the occupational therapy thing and she struggled it was only just before she died that she actually got an odd rail put on here and there and I think back now and I think to even the bits of stuff that I've got what a difference that would have made to her then".

# 6.3.2 Super-ordinate Theme: Assistive Equipment: is it?

Within this sub-theme I will consider the participants perspective of equipment and its impact on factors such as quality of life.

### 6.3.2.1 Highlighting the benefits and pointing out the limitations

All the participants were concerned for their safety when participating in activities of daily living, particularly those associated with kitchen and bathroom areas. Andy stated, *"I was very very afraid of slipping in the bath tub"*. For Andy, the solution was simple:

"they've given me steps I've got one side my pedestal wash basin put my hand on it one hand on my grab bar I can go in now very very easily and also the grab bars hold the bars before that I can't I have to hold it one my shower hose one hand now I can hook it and hold my grab bar and I can have a nice shower coming out is a grab bar so I can fully dry myself now in on the bath so it is tremendously helpful".

The provision of the bath step and fitment of the grab rails resulted in a positive impact on Andy's ability to access his over bath shower. Prior to this, he had expressed a fear of falling when attempting to undertake this task. His ability to now "*have a nice shower*" demonstrated the equipment's practical use in terms of being able to continue to access the shower and the overall effect this had on his quality of life. In addition, the provision of a mop rail enabled him to continue to engage in established routines and activities of importance to him:

"I usually take my morning cup of tea upstairs cause I have to have something to read when I have my cup of tea otherwise it is a waste of time waste of a nice cup of tea [...] so I take I mean normally ... health conscious I mean safety conscious people would not allow me to take my drink upstairs but now I've got the rail so I can I can hold it in my cause there is a fixed rail already on the right hand side nothing on the left hand side no I can hold my cup of tea in my right hand and hold the new hand rail and I put a hand on my banister".

Similarly, Billy described his fondness of cooking, taking great pleasure in preparing the main meal of the day. The dish he described below, particularly from the perspective of a non-cook, required some skill which he took pride in:

"B: I like cooking as well, I like baking [...] more cooking than baking I tend to do lunches most days or dinner if it's more convenient R: okay what kinds of things do you cook
G: anything I've if my favourite dish is haddock on a on a salsa base salsa then haddock then tinned tomatoes and herbs and cheese and grilled it's very tasty".

Prior to the provision of a simple piece of equipment (perching stool), similarly to Andy, due to a high risk of falling Billy struggled with this task. Though the equipment had reduced Billy's perceived risk it had not eliminated it to the extent he would cook when alone in the property. His wife was always ready to hand:

"she's always waiting for a for a shout if I need any help she comes through I tend not to cook if I'm in the house on my own [...] be asking for trouble [...] I sit on a perching stool as often as I can in the kitchen because if I stand and I'm working on the work surface my legs my feet manage to get further and further apart and I end up doing the splits".

Here, the benefits of equipment were highlighted without claiming to eliminate all risks and challenges. While Billy welcomed the support from his wife, he later indicated a desire to be less reliant, where possible, on his wife and remain independent:

"some of the things I need help from my wife but other things if I've got the aids I like to be able to do things myself ... it's a difficult subject".

Billy's comment on the difficulty of the subject is thought provoking. It implied Billy may struggle emotionally with his reliance on others and equipment as his level of independence wains. Without the step provided to access their shower cubicle, Mattie stated "*my showers'd be quite limited which I'd hate*". She reiterated how her "*self-esteem*", "*pride*", and overall "*independence*" would be affected with the need to be reliant on her husband. In contrast, when referring to her bathing equipment, Denny was reconciled to her limitations and appreciative of the opportunities it afforded:

"it has helped a lot cause you know if I can't actually get into the bath it's nice to have something I can just sit on top and don't have to worry about getting too far down and I don't stay in the bath very long anyway the days of me relaxing in the bath are gone none existent anymore and I actually cracked the edge of my bath trying to get in and out before I actually had the seat so it actually does help getting in and out".

Equally, Denny balanced their perception of equipment utility and its benefits. For example, when describing her use of equipment to facilitate toilet and bed transfers her experiences were mixed. Denny appeared uncertain of the efficacy and usefulness of the equipment:

"next to the loo not very much I mean it helps me when I'm not feeling too good and I need something to pull up on cause I was using the toilet roll holder to try and pull myself up so it has helped a little bit but you know when you're having a seizure you're half dazed anyway so it doesn't really make a difference but the bed ones been brilliant cause I can actually get up out of bed only I wish my mattress was a bit better cause I can feel it coming through the mattress underneath [both smiling and laughing] but apart from that yeah it's not too bad yeah [...] mmm I mean it's helped a little bit but it's still hard to get in and out anyway but that's just my medical condition unfortunately but it has so I actually pull myself out of bed so". In contrast, Fran was clear about the benefits of toileting equipment to both him and his wife, clearly stating, "*we both use it*". Albeit with some prompting, Fran proceeded to express the virtues of the equipment on maintaining his independence:

"R: so would you miss the frame than if it wasn't there then is that what you're saying
F yeah
Wife: yes
R: so if it wasn't there again what kind of impact do you think that would have if you didn't have it what kind of effect would that have
F: it would make life more difficult ... yeah
R: would you be able to go to the loo still on your own do you think or would it be tricky
F: no if I got to go without that frame no ... a definite no
R: so it's quite useful then
F: no it's more than that it's essential".

Clearly, Fran's final comment indicated how his ability to access the toilet would be severely compromised without the toilet surround. Alternatively, several participants levelled their disappointment when equipment failed to meet expectation. Tony and Robin were vocal about the poor performance of their respective sock aid and toilet seat/frame combined:

"they did bring me a sock aid but I can't use it doesn't work ... [...] if it'd been the plastic one it might have been alright but the sock wants to grab to that and not let me ... push into it and it makes it harder work than not I let her put em on" (Tony).

And:

"I got onto the toilet or whatever and I thought hang on a minute I can't do nothing here this is bloomin no good and I were cursing everybody but meself yeah what have they brought this bloomin stupid frame I can't even turn me legs round here I'm gonna end up killing meself here do you know what I mean cause seriously I was there I was like I couldn't I couldn't even cause my knee there's up against like a say it's there and then the you've got it's only about this wide ... do you know what I'm saying so I'm sat there me little bum fits in alright [both laughing] but it's just this piece here so when I'm trying to ...go round there to clean meself it just won't happen so that's when I ragged it out like I like I say I've chucked it in the bath it's upside down in the bath" (Andy). The poor utility of small equipment items was further highlighted by Billy and Denny. Billy recognised the functional worth of some items, however he was as equally disparaging of those which failed to meet his expectations:

"small items that may seem irrelevant but make a tremendous difference combined spoons and forks you had to buy they didn't supply those button hooks two different types one with a wire and the other more traditional ones with a hook and I need I need them both some work better on some shirts some on others sprung walking sticks you know those you can buy anywhere in these discount stores I find a solid walking stick not a lot of use but the sprung ones helps me keep my balance they're very good oh these torches ...very large bowls great big bowls that you would get pasta in in a restaurant you can they're very useful I can eat with a reduced area of damage very large bowls err numerous types of pill boxes pill cutters timers alarms with any of those but I've had to buy them all they're not dear but sometimes they're a waste of money because they don't do what you expect them to do".

During his interview, Robin, a self-confessed "gadget freak", produced a box of small kitchen items all of which he had privately purchased. Robin took great delight in demonstrating each item, including peelers, can and jar openers and a portable car door handle, whilst providing a running commentary on their advantages and disadvantages. Whilst Robin expressed some of the benefits and inadequacies of equipment design, others were hindered by the design of their environments:

"the kitchen's only narrow so if you'd gor'it sat I was tight up to the worktops and if I turned it a bit cockeyed it would only go so far so it was a bit ... bit awkward in the kitchen [...] yeah it was just a bit it was just a bit big [...] just a bit big really the height and everything was just was perfect but it were just ... too tight" (Tony).

*"it is just a shame as I say with the layout of the house that the rails just aren't practical and that's no fault of anything only the building itself"* (Mattie).

Several participants sought out their own solutions which did not involve equipment designed for those with a disability. For example, after finding the perching stool offered by the occupational therapist as ineffective Tony sourced a non-specialist stool for his kitchen, " *have found a little wooden four legged stool round top which fits in ideal and I can sit on that it's right height so that works for that*". Other, common everyday non-specialist items were privately purchased by participants:

"we had a microwave we've had to get a new one for her that we could set the marker for her to use it" (Tony).

Here Tony refers to 'bumpons' which are used for those with a sight impairment to mark specific points on appliances such as microwaves and washing machines. Problem solving did not affect several of the participants, in fact they were keen to recognise areas they were struggling with and find their own solutions:

"we keep thinking what would make this easier and what would make that easier but ... sometimes there isn't owt you've just got to work round it" (Tony).

Participant reservations were also noted. For example, when offered a perching stool Mattie described her initial reticence. However, once in place Mattie's opinion was reversed:

"often I'll just go plonk on it for a couple of minutes which just gives you they do give you a lot of relief so I know as I say when [name] brought it I thought oh [gives look] that's gonna be a bit strange how's it gonna you know what difference is it gonna make [...] and I couldn't believe the difference that they actually do make [...] when you're cooking or something as I say I just go and plonk on it but the trouble is if others come in and they grab it first they'll grab onto it and I say off".

This sub-theme highlighted mixed responses to the utility and use of ADL equipment with several participants providing both positive and negative experiences. As such, ADL equipment can assist service users with their everyday activities. Equally however, it also highlighted how everyday equipment can be as equally useful. Despite his reservations with some of the equipment, Billy summed up his opinion quite succinctly, *"if you were to take all my aids away I don't know what I'd do"*. At this point, Billy experienced an emotional response; he cried.

### 6.3.2.2 Accepting and declining

When asked directly, all the participants indicated they would be uninfluenced by the aesthetics of equipment. Their primary assertions were associated with functionality and utility. However, contradictions to this claim were noted:

"what it's going to do for me is the most important thing, I don't give a toss [R laughs] to be honest to how it looks [...] you know I mean I have to this come spring summer I have to paint it because it is at the moment bare

wood but who cares I don't give a monkey to how it looks but how it affects me how useful it is I mean you know I am always like that oh yeah [...] just how useful it is that's the main thing you know yes I've got a very high opinion about it" (Andy).

Similarly, after first commenting on the importance of functionality Billy then reverted to suggesting aesthetics were of some importance:

"I've never refused anything cause I don't like the look at of it, if people are good enough to supply you with it I'll use it [...] the important thing is not what's stood in the corner of the room or it's how it helps me move".

"I've had the bath taken out cause it just got like every time I tried to step over into it I fell so we got rid of the bath and I got a walk in shower we haven't changed it to a wet room quite I wanted to keep it looking .. nice cause they're a bit clinical aren't they wet rooms".

However, in the first excerpt, Billy initially referred to equipment provided through statutory services before reiterating in the second part that functionality was a key ADL equipment factor. Whereas in the second excerpt, the shower was purchased and fitted privately. As such, whether Billy's opinion was reflective or dependent on the functionality of equipment was unclear, unfortunately the opportunity to explore this further was missed by the researcher. For other participants, the idea of family or friends 'seeing' equipment was of some concern to them:

"it's a toilet seat that sits on it err it's a riser but like I say I'm a bit a prudish you know like if me mam comes and me sisters come and them little kids come do you know what I mean I don't want em seeing all that" (Robin).

Here Robin reiterated feeling humiliated by others knowing he is struggling with certain activities such as accessing and using the toilet. He appeared more concerned about what the equipment implied rather than the equipment itself. The concept of 'not being seen to be disabled' was mirrored by several participants. For Mattie, her perspective of the aesthetics of equipment used within the home was more acceptable compared to that used outdoors. When referring to kitchen and bathing equipment Mattie stated:

"I think like the perch stools and I mean the steps and everything because of the job they're doing you expect them to look at bit more utilitarian [...] you don't expect something that's sort of really fancy or really up to date so I think they are you know I think you accept you need em and they do the job and they're fine so I've got no complaints on that score with it at all".. However, when asked to elaborate on their choice of using a child's pushchair over a four wheeled walker Mattie's perception differed:

"I think probably because yeah I am what sixty two but I think probably [laughing] because err it's just one of those things isn't it that you just don't want to feel as though you're old and you need this appliance that looks like you know that looks like well looks like an invalid appliance sort of thing I think isn't it [...] I think it is probably yeah it's not the equipment no I think it's the actual perception that [sighs] it's silly int it I think it's you don't want to be seen ... wheeling that round because you think oh it makes me look old and decrepit type thing or something and also I think it's yourself that you don't want to admit that you to [laughing] [..] gives me another few years before I've got to give in but no that's nothing to do with the equipment I've I mean because whatever however you design that it would look like a walking appliance and I think it's just that like you say it's just your own perception of I don't want to be seen using one" (Mattie).

Mattie was concerned here about the perception of others, how they would 'see' her which indicated concern for her sense of personal identity. This was particularly evident in relation to her age, which she perceived as young, alongside her association of equipment with 'older disabled people'. Mattie inferred the equipment may benefit her but to accept it would be a sign that she had given in, a decision she was not yet ready to have made.

Whereas for Tony, when considering the topics of utility, practicality, and aesthetics he was clear that whilst the latter was a consideration of his decision making, ultimately the utility of the equipment was the most important:

"what it can do but it it's practicality side of it ... like I said the one we had from mum was a big clumsy thing that ... every time anybody else wanted a bath we had to take it out and I don't really want to go that way I'll it's just a matter of finding ... [...] finding the right one yeah [...] as long as it functions no we're not we're not fussy on appearances well yeah to an extent you know what I mean as long as it's tidy it doesn't ... there isn't many most things I've had a look at on the internet are quite ... reasonably ... err what ... to look at they're ... tidy".

An influential factor underpinning Robin's decision whether to accept or decline equipment was whether it had previously been used by another person.

"I don't know if it's been used that toilet thing or if it's new ... right now if it's been used I don't want it in my house even ... that's me as an individual yeah I don't know if you'd be the same would you wear the same underpants and socks that've had on ... there's your answer do you know what I mean I don't know what's been happened to that I don't know you know somebody could have keeled over on it as far as I know you know what I mean they've maybe had blood whatever all over it [...] if I knew it'd been used I wouldn't want it my house ... that that's my personal bit".

Generally, most of the participants indicated the aesthetics of equipment would have an impact on their decision whether to accept or decline equipment. This was most apparent when referring to equipment most likely to be 'seen' by others.

### 6.3.3 Super-ordinate Theme: Making things better

The following sub-theme examines the concepts of inequality and disparity amongst differing service areas.

### 6.3.3.1 To have or not to have: who decides

Indirectly, issues surrounding the local criteria for equipment provision was raised by several participants. One example, described by Robin, involved his experience of being promised two sets of settee raisers by the occupational therapist who visited. Robin clearly considered this would improve his quality of life by offering him a choice of where to sit. However, when the technicians visited to deliver and fit the equipment, Robin was informed by them that he was entitled to one set and must therefore choose his preferred seated position. For Robin, the disparity between the two areas of practice was frustrating and incomprehensible:

"so the systems said to me right so you will sit here all day that's it sit over there and you'll be in pain ... what do I do ... what's the alternative for me [...] I've got to sit now and work that out meself do I either go out and see if I can buy these and put em on meself ... do I ask the God above is there somebody there to help me do I ring the powers that be and say can you bring me another four of these out even though I've been told that I'm only gonna get one set but yet the woman that come here first said no you need em on both because you use both settees".

Furthermore, this highlights the inequality between the rationale and clinical reasoning of the occupational therapist in contrast to the criteria the technicians follow. This raises a debate surrounding the need for clarity in terms of which is the most valid viewpoint, for example that of the clinician making decisions based on individual need, or those who control the purse strings. The overall outcome however was the impact on Robin's quality of life:

"I mean there's nothing you can do is there really I feel that it's wrong because I don't have a choice now I have to sit here so if the sun's blaring into there I've got to close these curtains like I'm a recluse in my own home I don't have a choice to get up and think well I'll sit over there I can sit over there".

Furthermore, Robin perceived discrimination by some members of staff:

"your co-workers or whatever you wanna call em they came and they suggested when I walked up stairs and came down they said to me I needed another bannister on the other side which they came out to do it and soon as they said no we're not putting it up I said why not they said because it's a studded wall well all modern houses are studded walls so I said everybody that's disabled who's got studded walls can't have another bannister".

The recommendation of equipment as an alternative to major adaptations was deeply censured by Robin who felt dehumanised at the suggestion of using a commode:

"he [doctor] told me buy screens and get a commode and do me number one and two in me front room and if's you've got friends and family just tell em ... it's life you've got to do it ... how degrading that is [...] I can't get me toilet done ... but the answer to it is to get a bucket down here and tiddle in me bucket ... they're not bothered about if I dribble all over the carpet or have a bit of a mishap and the embarrassment it'll cause me and when my cleaner comes round ... and there's excrement all over me furniture if that was to happen and it hasn't happened but if it did it's that's no human way to get to carry on surely".

Robin clearly believed his sense of dignity and identity was being unfairly and unacceptably challenged. Equally, following a fall downstairs when accessing the toilet, a certain false economy or irony was not lost on him:

*"it must have cost thousands and thousands of pounds it'd have been cheaper to put my toilet in there just to go in there and have a wee than go up and there and fall back down ... I don't know [smiling]"* (Robin).

#### 6.3.3.2 Action rather than reaction

Andy qualified his indifference to the aesthetics of equipment when introducing the topic of preventative interventions. Whilst acknowledging the NHSs imperfect nature, Andy associated occupational therapy with a potential for reducing risk. He asserted the importance of equipment provision in preventing injury and its consequences:

"look wise as I say look wise it doesn't look very good, but who cares as long as it I gets hold onto something before I fall that is the that is the way it should be proactive don't let the people fall [...] as early as possible as early as possible [...] rather than waiting for something to happen".

"well lot of people criticise NHS I don't to be honest with you they have a problem no not everything is perfect let us face it but think why occupational therapy given me equipment I think the thinking behind it is that don't let the people fall take action before it happens [...] don't let the people suffer take the action before so proactive".

The need for proactive interventions was mirrored by Fran's son following personal experiences of being part of and navigating the health and social care systems. He described his experience of the lack of communication and holistic assessment:

"Son: my only observation would be is that he only gets assessed I know it sounds strange when he's ill what it doesn't take into account is the aging process ... [laughs] [...] it was only when he was hospitalised that he has been fully assessed on both occasions [...] unless he was back in hospital again my observation is there's no other review in place and of course his needs do change

*R*: so what do you think the answer is to that then Son: I think he needs a bit like an annual MOT".

"the other bit that I've noticed is it tends to be everything is either about dad or it's about mum with her illnesses what they don't do is assess them as a couple because what happened when dad went into hospital mum struggled cause they kind of compensate for each other and that's the bit where you know as an observer to what's going on obviously a very concerned observer that that's the bit where it doesn't look it could be more co-ordinated" (Son).

"what we always find is that is when he's in hospital ... he's not released [laughs] until everything's fine ... and recently with the carers I when dad was in I had the carers dealt with my dad in the hospital and we had an appointment here to see my mum because she'd got her own needs and then I had to get the two departments to talk to or the two people to talk to each other cause I kept saying you've got to view them as a couple so somehow as I say ... the utopia the best would be something like once a year old people are assessed in their own home and to see to see how they're getting on" (Son).

#### 6.4 Reflexive thoughts and ideas

A small number of the participants in this sub-group were less demonstrative and more discreet than their peers. As such they were more reserved in their responses which affected the length of the interview and at times the detail they captured. Although I was aware of this, and attempts were made to encourage the provision of more detail surrounding the event or experience this was often not forthcoming. Following the relevant interviews, I questioned whether at the time I should have been more assertive or probing. While this may have been appropriate in some instances, as with the previous two sub-groups, I became aware of a sense of anxiety at the thought of probing inappropriately and therefore raising the emotional responses of the participants or ethically compromising my role and values as a researcher and an occupational therapist. As an occupational therapist I am used to 'probing' during conversations and assessments however, following further reflection I now also believe there was an element of anxiety surrounding the possibility of jeopardising my ethical approval. In hindsight, discussing this further with my supervisory team and other IPA researchers would have been both helpful and proper.

### 6.5 Summary

Chapter 6 presents the findings of the seven service users who consented to be interviewed for this main research project. All the participants had been seen by an occupational therapist and were in receipt of ADL equipment. As with Chapters 4 and 5, interview extracts have been selected to support the super-ordinate theme and subthemes.

As found in Chapters 4 and 5, the concept of identity was as evident. The service users were mindful of the impact of their diagnosis and the equipment on their identities and those of close family.

The following chapter explores the issues raised within the previous three chapters before relating them to the literature. Implications to occupational therapy practice, the limitations to this main research project and future research are all considered.

#### **Chapter 7: Discussion**

The three previous Chapters (4, 5 and 6) focussed on the findings of each individual sub-group: the clinical leaders, occupational therapists, and service users respectively. Each chapter provided information related to the participants and interview dynamics before presenting the findings. The findings were presented using the structure of the super-ordinate themes and sub-themes developed during the analysis process. All themes were supported by a range of interview excerpts. This process embodied the essence of IPA as the researcher attempted to make sense of the participants understanding of their experiences, in this case occupational therapy and ADL equipment.

Chapter 7 comprises of several sections. The first, Section 7.1, re-examines the findings of the three participant sub-groups. This facilitated the opportunity to explore key themes which arose within each, between two or across the three sub-groups. In addition, whilst maintaining the homogeneity of the three distinct sub-groups, the overarching themes are explored in greater detail and discussed in the context of the existing and wider literature including national and international occupational therapy and psychology papers and texts. Unfortunately, there was little direct relationship between the content of the nine studies included in the Literature Review (Chapter 2) and the findings of the main research element of this project. Whilst there are some similarities the basic level descriptive analysis of Chapters 4, 5 and 6 indirectly supports the findings of the nine studies. For example, reference is made to issues of equipment abandonment, safety and aesthetics by the participants of this research. All nine studies focused on the practicalities and functional outcomes of equipment use. While the information they gathered had the capacity to offer some insight, in terms of the participant experience this was limited or absent. Section 7.2 outlines the arising implications for occupational therapy practice. The limitations of this research project are identified and discussed in Section 7.3, Section 7.4 focusses on the topic of reflexivity and Section 7.5 concentrates on the potential for future research. The final section (7.6) presents an overall summary of the chapter.

In total, 26 participants consented to be interviewed. Of these, nine were occupational therapists with a clinical leader role, 10 occupational therapists and seven service users. The clinical leaders and occupational therapists were employed by one NHS Foundation Trust. The service users had all received assessment and provision of ADL equipment by occupational therapists employed by the same Trust. The clinical leaders

were responsible for their own caseload [and other duties] and overseeing junior occupational therapists. None of the participants asked to withdraw from the research following their interviews.

# 7.1 Bringing the findings together: the overarching themes

Within the three sub-groups, each participant had experienced the phenomena of occupational therapy and ADL equipment. Each sub-group represented a homogenous sample, namely from the perspective of either clinical leaders, occupational therapists or service users. As presented in Chapters 4, 5 and 6 a range of super-ordinate themes and sub-themes were developed during the process of data analysis and writing. The super-ordinate themes from each of the three sub-group are as follows:

- > Clinical leaders: a question of identity, the practicalities, and moving into the future
- Occupational therapists: restoration or compensation, the practicalities, and moving into the future
- > Service users: loss and grief, assistive equipment: is it? and making things better.

As previously stated, the data analysis and writing process for each chapter took place independently of the others with a conscious effort to 'put aside' the findings from any previous analysis which had taken place. Naturally as the researcher and analyst I was aware of the findings of the previous chapter/s and took conscious steps to prevent this knowledge from influencing my thoughts. A strategy adopted involved constant travel between the transcripts, my initial notes and analysis through to the final draft. Whilst the similarities of the interview schedules should be acknowledged, the variance of the interviewees' recollections and thereby the content of the transcripts reflect the participants' own individual experiences. However, common points of interest arose naturally during the data analysis process which is in part reflected in the superordinate themes above and the sub-themes within each of the three chapters. As a result when exploring the similarities and divergences across the three preceding chapters (4, 5 and 6) overarching super-ordinate themes became apparent. This was not an intentional outcome but rather a commonality of issues arising across the three sub-groups. The first overarching theme common across all three sub-groups is the concept of 'identity', which according to Smith et al (2009) is an unintentional though recurrent thread found within many IPA research projects. The second over-arching theme is 'professionally speaking' which involves issues concerning occupational therapy clinical practice. Figure 7.1 below demonstrates the relationships between occupational therapy and ADL equipment and its association with the overarching

themes derived from the three sub-groups. Whilst these concepts are defined and presented separately, an interplay between the overarching themes remains.

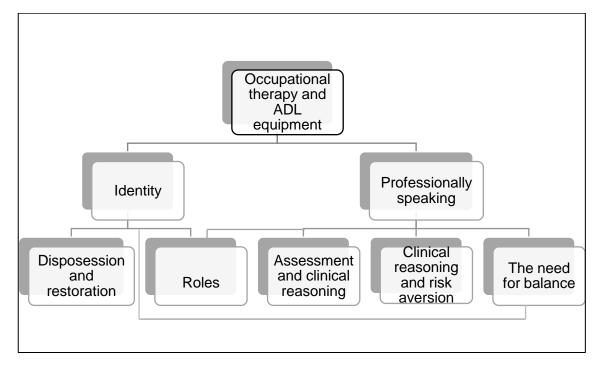


Figure 7.1: Overarching themes – collective themes derived from the three sub-groups

# 7.1.1 An overarching theme: 'identity'

According to national and international literature including (Vignoles 2017, Talaifar 2018, APA 2020, Gross 2020) the concept of identity or the self encompasses characteristics which make us who we are as an individual being; in essence our identity defines us. As humans we exist as part of our personal and social identities, in other words our self-distinguishing characteristics and those which are common to others respectively (Devos et al 2014, Talaifar 2018). Others, including Christiansen (1999) and Carlson et al (2014), also provide links between our sense of self and identity to our occupational choices. Our sense of identity incorporates self-esteem, self-image and our ideal self which affects how we perceive ourselves and how we believe others perceive us both now and in the future (Oyserman et al 2014, Talaifar 2018). A large volume of psychology literature including Ismail and Tekke (2015), Mann (2016), Talaifar (2018) and Vinney (2018) attribute this theoretical approach to Carl Roger's, one of the pioneers of humanistic psychotherapy. Self-esteem involves our personal values and how we appraise ourselves as an individual, whereas self-image incorporates how we view ourselves including our personality traits, our physicality and social roles. The ideal-self is the image of who we strive or would like to be (Vinney 2018, Gross 2020). Our identity can be affected by social factors, the physical

environment and the situational context (Christiansen 1999, van Huet et al 2011, Oyserman et al 2014, Stets 2018, Talaifar 2018). An individual's sense of self or identity is therefore defined by a set or collection of unique characteristics and roles. A loss of identity involves a change in our sense of connection to the world and the perception that we have 'altered' in some way from the person we knew before (Davies 2008, APA 2020). As highlighted throughout the findings chapters of this research (Sections 4.3.1.1, 4.3.1.2, 5.3.1.1, and 6.3.1) participants within each sub-group experienced or described their relationship to loss and grief. While the concept of identity and the self is in a constant state of flux (Oyserman 2014, Talaifar 2018), a change in identity caused by ill-health or diagnosis is forced rather than being the result of natural adaptation and change based on experience. Where natural change occurs the individual retains many of the characteristics that make them who they are. For some, an enforced change in characteristics, such as a change in health status, combined with the lack of control this generates can be catastrophic and longstanding to both our personal and social identities (Smith and Osborn 2007). It could be suggested that the inability to continue to conform to our perception of social norms and expectations is inconceivable to some service users. Christiansen (1999) explored their perception of the concept of identity and occupation. They asserted how the reliance between the two results in an individual's capacity to communicate, articulate and express the concept of self.

Within this research there was a sense that ADL equipment had the power to provide or restore service users with an identity which may have been 'new' or modified in some way. This was particularly evident from the perspective of the clinical participants. However, whilst the clinical leaders and occupational therapists recognised this they also acknowledged some service users were less accepting. Therefore while the benefits of equipment provision was recognised by all of the participants the concept of identity and self may explain the deep seated reluctance of some service users and their choice not to accept ADL equipment. It is therefore important for occupational therapists and others to rationalise this, explore the motives of the service user's choices and consider alternative solutions. All of the participants were affected in some way by the concept of 'identity' personally, professionally or both.

Within the UK literature, little evidence is available surrounding the concept of identity in relation to occupational therapy and ADL equipment. An exception is Milne (1988), who referred to the children within their research as individuals rather than their

diagnosis. Milne (1988) recognised the participants' functional ability was of greater significance compared to their condition/s when identifying equipment suitable for bathing. Other literature (Polatajko 2014), though not referring to equipment, acknowledges that a diagnosis or condition does not define who we are and that we are affected by other internal and external factors. Understanding this is necessary and important during the decision making process as it recognises individuality amongst those who may have the same or similar diagnosis. Within this research and anecdotally via the experience of this researcher, there is the suggestion that local decisions to approve/supply equipment is condition-led rather than based on the individual needs of the service user. Whilst the decision-makers may refute this, feedback from peers and the researchers' attendance at 'panel' may suggest otherwise.

## 7.1.1.1 Dispossession and restoration

Located within the concept of 'identity' was a sense of loss and/or gain experienced by members of the three sub-groups. With regard to the clinicians and service users this affected their professional or personal sense of identity respectively.

For the service users, their sense of loss manifested through an acute sense of guilt which resulted in both personal and equally, if not more importantly, the loss others had experienced. Ultimately, they grieve for what they and their families once had or could have. On the other hand, many of the same participants recognised the routines and occupations which could be gained by the provision of equipment. The importance and benefit of maintaining an equilibrium is demonstrated by the voice of one of Goodacre and Turner's (2005) participants:

"Without it [stairlift] my husband and I would not have been able to spend the last of his time sitting downstairs taking part in everyday things, meals at the table and sitting in his chair." (p95).

Further to this, the description offered by the participant indirectly acknowledges how the couple were able to maintain their relationship as they appear to have continued to sleep upstairs, presumably together in the same space. Whilst it is likely the couple would have been experiencing 'loss' and grief during this period due to the stairlift they were able to maintain their spousal roles by remaining together within the environment. Several of the service user participants in this research referenced their own experience and consequences of pain. Davies (2008) highlights how individuals who experience pain are prevented from participating in meaningful activity. They (individuals) may withdraw from their social contacts in an effort to protect themselves from factors such as being judged by others, their self-esteem and being or becoming a "burden" (Davies 2008, p232). Equally, several participants in this research project either directly or indirectly identified how they had 'changed' as an individual over time; a concept supported by Davies (2008).

## 7.1.1.2 Roles

A further link between the concept of identity and dispassion and restoration is 'roles'. Ultimately, from a clinical perspective the provision of ADL equipment has the capacity to return service users and those who support them to a preferred or required role, for example as a spouse, homemaker or parent. Or, generally the ability to undertake a functional role where equipment has restored independence or decreased dependency levels. The service users were as equally aware as the occupational therapists of the impact of an altered 'identity' on their role perception. Many identified a shift in the relationship between themselves and family, namely there was a suggestion of role reversal or of family having taken over roles previously completed by the service user. While the service users appeared to accept the change in roles out of necessity, the acceptance was more often tolerated rather than well-received. A change in role affected all of the service users, either directly or indirectly this coexisted alongside a sense of loss.

Participants' 'sense of self' in relation to pain was explored by Smith and Osborn (2007). Whilst the phenomena of equipment under study is replaced by pain, the participants highlighted how their perceptions of others' responses greatly affected their sense of self. Linked to this was the effect of pain on the ability to engage in and achieve roles and the sense of shame this evoked. This was not dissimilar to the experience of the participants who took part in this research project, particularly when referring to the cause and effect of pain on roles. As Smith and Osborn (2007) pointed out, the findings of their research may not have represented the feelings and experiences of others. However, as their participants and those within this research described similar feelings perhaps it could be considered possible that feelings of shame are in fact common. As Smith and Osborn (2007) suggested, further research exploring the phenomena could be useful in helping clinicians understand and better support individuals. The implication of this for occupational therapists is that many

service users would benefit from some form of psychological input alongside the act of assessing for and providing equipment.

From a clinical perspective there are two aspects to the role concept. The first, the fundamental role of the occupational therapist to assess for and provide equipment is discussed here whilst the second, the impact of extrinsic factors, is considered in Section 7.1.2.1. When referencing the future of occupational therapy, the majority of participants were positive. However, several clinicians expressed concerns and misgivings particularly in relation to the future identity of the profession. Despite this the overall consensus that equipment would remain a 'tool' for occupational therapy practice was strong but under what guise was less clear. For example, several participants indicated that equipment would no longer be the exclusive domain of occupational therapy practice. A number of the occupational therapists were clearly uncomfortable with this notion suggesting how other professions lack the skills and knowledge which they perceive surrounds the assessment and provision of equipment and which the profession of occupational therapy excels in and aspires to. Similarly, there was concern that the increased dependency on, and consequences of, equipment over prescription is counter to the core principles and values of occupational therapy practice. However, belying these concerns is the inference that if 'equipment' provision becomes a generic skill it may cause problems for the long-term future professional identity and core role of occupational therapy practice.

Gardner and Shulman (2005) provided a list of six generically applied professional characteristics. While all six apply to the profession of occupational therapy and others, the third – "mastery of a domain of practice" (p15) – appears particularly pertinent to the concerns of the clinicians in this research. As such, if a disassociation between occupational therapy and equipment occurs alongside a greater association of equipment with other professions, according to Gardner and Shulman's (2005) theory, a key component of the identity of the profession of occupational therapy is at risk as we know it. Several clinicians in this research feared this may accelerate the end of the occupational therapy profession, whereas for others this may enable the profession to evolve. Much of the literature pertaining to the concept of professions (e.g. Fitzgerald 2020). The consequence of strong and poor professional identity is common within the literature as highlighted and discussed by Clouston and Whitcombe (2008) and Fitzgerald (2020). Furthermore, many, including Clouston and Whitcombe (2008), Grant (2013), Turner and Knight (2015) and O'Shea and McGrath (2019) discuss the

lack of clarity surrounding the identity of occupational therapy, both nationally and internationally. Does this then imply that the centrality of equipment provision as part of professional identity, as observed in this study, is common across the whole profession? Perhaps this in an area requiring further research to explore whether professional identity is contextually and/or organisationally related. For example, is 'identity' a product of culture linked to individual context such as a service or department or does its origins lie within the organisation as a whole.

### 7.1.2 An overarching theme: professionally speaking

The following theme assimilates the issues and concerns which specifically relate to the clinical practice of the occupational therapists interviewed as part of this research. It focusses on the concept of roles, assessment and clinical reasoning including risk aversion and the act of balancing equipment provision and non-provision.

### 7.1.2.1 Roles

As reported in Section 7.1.1.2 the concept of identity and roles is revisited here, particularly the impact of the establishment and policy on the role of the clinicians which in turn affects the fundamental ability of the therapists to provide equipment. There was an unspoken consensus between the clinical leaders and occupational therapists who collectively identified factors relating to the cause and effect of this phenomena. For example, a change in the ethos of health and social care which many now consider is no longer representative of that of the therapist. Several participants recognised how local policy reflects the national guidelines which compels service users to convalesce in environments other than a hospital ward. As such, provided service users are 'medically fit' they are expected to continue their recovery elsewhere, namely at home or an alternative environment such as a rehabilitation or enablement unit. As a result, this cultural shift has cultivated an emphasis or expectation that equipment provision will provide a quick simple solution to timely discharges. However, several of the occupational therapists expressed how the need to expedite discharge was not congruent with the principles of occupational therapy practice and as such many struggled with this compensatory approach. Conversely for others, the belief existed that hastening discharge returns individuals to their desired environment with the potential to accelerate recovery. This broad topic is touched on briefly by Cooper (2006) who acknowledged that a delay in equipment provision does affect timely discharge. While referring specifically to equipment within palliative care, Cooper (2006) was clear in their suggestion that occupational therapists must be mindful of the needs of their patients and plan swiftly and accordingly in line with available funding and resources. Cooper (2006) aligned the ability of occupational therapists to be proactive rather than reactive as an essential element of student education. Having worked within the area of palliative care and with service users who have reached the end of their life, the need to facilitate rapid discharges is understood by this researcher. Equally, the impact and fallout of hasty discharges with dour consequences have also been witnessed and reported by other occupational therapy and professional colleagues. As such, whilst understanding change in local and national policy the needs of the service user should be a consideration when planning discharge to ensure safe and effective outcomes. This requires input from the multi-disciplinary team, including occupational therapists, to provide their professional opinion based on clinical reasoning which informs discharge from services with the best interest perspective of the service user; concepts inherent to the professional standards of the HCPC (2016) and the RCOT 2021a.

Further to this, many clinicians (either clinical leaders or occupational therapists) expressed an acute discontent related to their perception of a 'disconnect' between senior management roles and the reality of clinical practice. This tended to correlate most with experience surrounding funding and resources. Whilst the clinicians accepted the need for some form of control, they reported strong feelings of frustration and anger when supposing their professional integrity was being challenged. In addition the clinicians raised ethical concerns when aware of service users who had purchased equipment which they as a therapist considered unsuitable or unsafe. In accordance with professional standards (HCPC 2016a; 2016b, RCOT 2021a), occupational therapists and other professions accept service user's rights to make unwise decisions. However, the level of concern raised by the occupational therapists was heightened when potentially unsuitable purchases were linked the decisions made by the organisation. The consensus amongst the participants was that the most suitable equipment item is provided based on a robust assessment and should not be dependent on the availability of funding and resources.

#### 7.1.2.2 Assessment and clinical reasoning

The complexity of equipment assessment and provision was highlighted by all of the participants within sub-groups one and two. The approach to assessment and provision of ADL equipment used by the occupational therapists varied. Approaches were dependent on experience, knowledge, and pressure to perform and conform to service remit/s and organisational policy. Opinion generally centred on or was divided by the

perception of what constituted a holistic assessment versus a 'quick fix approach'. Here the debate surrounding dependency and independency and the use and non-use of equipment was frequently raised by the participants. While several of the therapists advocated rehabilitation over equipment provision to reduce dependency, others argued how equipment could be a quick and simple solution to a functional problem. This highlights the often multi-faceted direction of identifying the most appropriate clinical approach to solving service users' needs. As such there is not a singular solution to this issue but rather there is a need for robust assessments which identify the challenges faced by service users and, in collaboration with them, how best to resolve any issues identified. This requires the clinician to draw on their experiences, tacit knowledge and ability to clinically reason (Carrier et al 2010).

The professional literature (HCPC 2016a; 2016b, RCOT 2017; 2021a) is peppered with references to the clinicians need to use the most appropriate mode of assessment and treatment informed by clinical reasoning but within the boundaries of a/the service. It could be argued that clinicians are perhaps torn between the wishes of the service user, the values and principles of the profession and/or abiding by the needs of the service and the organisation. Either way clinicians should use their expertise in clinical decision making. This exact question of provision or non-provision was explored by Abraham et al (1987). Their research resulted in the development of a framework which structured the decision making process of the assessing clinician. At the time of the research Abraham et al (1987) extolled the virtues of the framework in offering management the opportunity to 'see' the process and outcomes. However, given the research was conducted over thirty years ago and the issue remains contemporary to current practice, this suggests the 'integration' of clinical, management and organisational decision making remains distant. Jeffrey et al (2021), who conducted research with 11 participants, posited that the concept of clinical reasoning begins during and then beyond the qualifying programme. They concluded that knowledge surrounding clinical reasoning and decision making is available through several sources. These were: research findings, policy and protocol, the service user themselves, experienced colleagues, and finally reflective practice. Further to this, Unsworth and Baker's (2016) review of the literature previously highlighted the need for further research to explore and capture how clinicians reason and to examine which approaches enhance the development of clinical reasoning skills along the novice-toexpert spectrum.

Clinical reasoning in this context should consist of an exploration of the purpose and meaning of equipment to the individual service or equipment user. This must include consideration of the topic of aesthetics which split opinion across all three participant sub-groups. For example, for several participants, equipment was simply designed for its utilitarian benefit and as such they deemed aesthetics unimportant. However, other participants indicated how the aesthetics was more critical whether referring to how it fitted with 'the look' of the environment or how the service users were perceived by themselves and others. For several of the participants the aesthetics or possession of ADL equipment projected thoughts of the users as being labelled as disabled or as dependent on others, whereas for others the equipment simply allowed service users to 'just get on with life'. Given the complexity of clinical need and service user perceptions many of the participants recognised the need for balance and compromise. Here, the subject of aesthetics returns the reader to the importance of the concept of identity, whether from the equipment user or the clinical perspective.

#### 7.1.2.3 Clinical reasoning and risk aversion

As highlighted in this research a core concern for the profession of occupational therapy involved a perceived cultural shift toward clinical practice which negates or prevents litigation. In addition, it raised concern surrounding less experienced staff who lack confidence and overprescribe equipment to avert risk which ultimately results in a circle of increased dependency. These members of staff are reliant on more experienced occupational therapists to guide their decision making whilst they develop from novice-to-expert clinical reasoners (Carrier et al 2010). The RCOT (2018b: 2021a) is clear when asserting how clinicians are expected to engage with risk assessment and management in relation to the needs of the service user in line with issues surrounding informed decision making and capacity. When interpreting the RCOTs guidance on risk (2018b) and their professional standards (2021a), clinicians who purposefully avoid or redirect service users away from positive risk taking and informed decisions are themselves at risk of professional misconduct. If not addressed, combined with the shift toward timely discharge, these issues will all contribute to a future workforce which is unable to clinically reason and a profession which is fundamentally risk averse. This highlights the need for confident occupational therapists who demonstrate and practice positive risk taking themselves and thereby are open to service users participating in life's risks and progressing toward independence and a lifestyle of their choosing. Occupational therapists must also be mindful of service users who will actively choose to make unwise decisions. These service users will benefit from the advice of occupational therapists and a duty of care

to offer solutions to take steps to reduce the risk/s surrounding these decisions. From a wider perspective the DH (2007) produced guidance for a range of practitioners engaged in health and social care. The guidance refers to the rights of service users to exert choice and control over their lives and whilst recognising this as a generally positive approach there are also risks and responsibility associated with this. Though the guidance was developed to support the 'whole' life of individuals the parallels between this and the professional standards are comparable and are easily translatable into occupational therapy clinical practice. Other literature which explores the concept of risk and risk aversion includes: Morgan (2004), Atwal et al (2011), Gallagher (2013) and Cross et al (2014). Both Atwal et al (2011) and Cross et al (2014) found that occupational therapists presented with a tendency to be risk averse rather than risk positive. Gallagher (2013) opined the necessity for occupational therapists to use their "creative skills" (p339) when considering risk and suitable solutions. By contrast, Morgan (2004) partitioned some of the responsibility of facilitating and encouraging positive risk taking within professional practice on the shoulders of management, particularly the shoulders of senior management. Morgan (2004) emphasised how encouragement from senior management would project confidence onto junior staff who would then explore risk in more detail and, with support, identify solutions which best fitted the wishes of the service user.

## 7.1.2.4 The need for balance

The information gathered from the project interviews highlighted some of the pros and cons of equipment provision from the perspective of the clinicians and service users. For the clinicians generally ADL equipment offers or provides an intervention option, however this is where dividing opinion can be observed. For some of the clinicians, equipment was seen as a primary solution to bridge the gap between dependency and independency and/or timely and delayed discharge. For others, the provision of equipment is considered useful for bridging a short term gap whilst working on longer term outcomes which may then negate the need for equipment. The latter participants were clear that whilst equipment had its place it was and should not be the only tool in the bag available for occupational therapy interventions. While equipment can be right for some service users and work in the short term to promote and enable function it can also be responsible for increased dependency. In addition, the provision of equipment too early in service users' rehabilitation journeys may prevent the potential for further improvement as the service user may become comfortable with the equipment and what it enables them to do. Alternatively in some services, dependent on their remit,

the provision of equipment may result in the immediate closure of the referral which may be detrimental to the service user continuing to make progress.

Equally, the timely or delayed provision of equipment affects the service user. Perhaps 'they' would prefer one option over another and would welcome the opportunity to make an informed decision rather than being influenced by service remit. Exploring what the provision of equipment would mean to the service user in terms of their short or longer term functional ability would be more in line with the person-centred approach of occupational therapy practice and place the service user at the heart of choosing what is right for them. The opportunity to make an informed decision may also assist with the psychological and emotional issues equipment provision raises in terms of the 'self' and 'identity'. Appreciating service users' understanding of risk in relation to the choices they are willing to make, and how equipment reduces their perception of risk is equally as important as exploring that of the clinicians. As such, occupational therapists who attempt to gain a greater understanding of service user's individual perception of and willingness to engage in risk will enhance the therapists understanding of choice and offer service users' additional information to enable them to make a clearer informed decision. Occupational therapists must continue to be mindful of risk and its consequences whilst also balancing this with the wishes and choices of the service users.

# 7.2 Implications for practice

The findings of this research project raises a number of issues surrounding the topic of occupational therapy practice and ADL equipment, and has highlighted various implications to current and future practice.

A key finding of the research project was the link between equipment and identity. The concept of identity was touched upon by participants within each of the three subgroups. With regard to the occupational therapists the topic of identity was both a personal and professional concept. While several of the participants in sub-groups one and two were ready and willing to embrace equipment and the profession, several others expressed clear feelings of 'threat' to their current and future professional therapy was at risk of 'disappearing' as other disciplines became more involved in the assessment and provision of equipment, and increased availability through other forums. A question arising from this perception is, as a profession, do we allow this to happen and then re-establish ourselves as part of wider specialisms or should we embrace change and actively position ourselves to become the experts at 'teaching' others 'how to do it' and consulting in complex cases. Equally, from the perspective of the service user and the therapists the lack of understanding surrounding the 'meaning' of equipment was raised. For some the equipment was perceived simply as 'what is was', for example a RTS or a perching stool, however for others there was an undercurrent which highlighted hidden or deep felt emotions which did affect if and how well equipment was accepted. For many of the service user participants the use of or need for equipment had a significant impact on them as a person, including how they identified with themselves or believed others identified with them. A greater understanding and recognition of this should positively affect our assessment approach and process which ultimately should result in equipment being issued that will be used rather than discarded and collected. Equipment provision should be focussed on the needs of the individual rather than what suits the organisation.

In addition, there were practical issues affecting occupational therapy practice, the service and ultimately the service users. On a simple level, before applying the principles of data analysis, several issues were raised by the occupational therapists whether in a clinical leadership role or as a Band 5 or 6 therapist. For example, participants in sub-groups one and two raised the contentious issue of 'panel'. While the importance of controlling provision was widely accepted, the degree to which this was regulated was challenged, in terms of job and career satisfaction, the morale of the staff, and the wider impact on service users. If this approach continues there will be consequences in terms of the well-being of the staff and their retention within the organisation and potentially the profession itself. Where recruitment and retention is already challenging this could have a devastating effect on the number of locally practicing occupational therapists. Equally, the Care Act 2014 emphasises the need to consider 'the individual' during any assessment process and is clear that a 'blanket' approach to decision making is not encouraged (Mandelstam 2016). This suggests that caution should be applied when applications or requests for equipment are made and declined. The guidelines provided by Mandelstam (2016) offer both occupational therapists and decision makers a framework upon which to base their initial or primary decisions.

Balancing the opportunity to provide or not provide equipment dependent on the remit of individual services is not an easy fit. However, a culture of poor assessment choices and equipment provision which favours speedy discharge from inpatient and community services will continue to affect the morale of occupational therapists and

service user outcomes. Furthermore, differences in timely or delayed provision and non-use of equipment (for example over-prescription) will affect others' understanding and perception of the role of occupational therapists and equipment. This will have the effect of undermining occupational therapists' assertions that they are best placed in both knowledge and understanding to be experts in equipment assessment and provision and may cause managers and stakeholders to seek alternative solutions. While some of the occupational therapists in this research were less concerned about the long term exclusive association between occupational therapists and ADL equipment, others were. As such, occupational therapists locally and nationally must re-evaluate the professional relationship between the two and seek to develop a future approach which harmonises the concerns raised by the participants in this research and enables some form of mutual agreement which allows the profession to move forward. Given the deep rooted association of occupational therapy and ADL equipment a shift away from assessment and provision may be unlikely. However, a solution which observes ongoing provision and expert consultation may be a suitable compromise. As a passionate occupational therapist with an almost continual clinical background in ADL equipment and wheelchairs I firmly believe there is and must be a continued relationship between the two. However, I also agree that equipment should be complementary rather than the primary solution to occupational therapy outcomes.

As highlighted in Section 4.3.3.1, recognising how gadgets are becoming increasingly inclusive into everyday life could be seen to diminish the need for simple provisions thereby making elements of the occupational therapy assessment appear more and more redundant. Furthermore, as there are drivers for service user involvement in the development of services, this should be taken into account when considering criteria for equipment provision. As such, consideration for who is best placed to understand the needs of the local population should be considered when appropriate and responsible decision makers are identified. With reference to traditional versus new technologies, this links to the concept of whether it is time for a new definition of ADL equipment. Although, the activity itself may remain unchanged the equipment is changing. As such occupational therapists need to adapt and adjust their role to incorporate advice and support about all types of equipment and technology. Equally, the perception of 'specialist equipment' could be challenged. For example, is it the equipment itself or should it be dependent on the needs of individual and the task at hand. Should ADL equipment be about what is important to the individual's lifestyle, however, conversely, is this a realistic possibility? This links into the concept of how the perception of equipment provision is now adapting toward the promotion of activities

and occupation as opposed to the historical approach toward identifying and addressing disability and dysfunction. The emphasis now is on ability. Overall, there was a sense that there should be a balance of equipment provision. However, the profile of the occupational therapy profession is challenged where the concept of 'over prescription' is raised.

The lack of sensitive outcome measures and current robust research surrounding the provision of ADL equipment and occupational therapy and therapists place services and the profession at risk of being unable to adequately support their presence in current and future health and social care contexts. Equally, when positioned in the context of the current financial climate and the growth of external providers additional pressure may be placed on traditional occupational therapy services to demonstrate their continued worth.

# 7.3 Reflexivity

The concept of reflexivity was introduced in Section 3.3.7. Reflexive thoughts and ideas have been provided toward the end of each findings chapter (4, 5 and 6). Here a range of collective reflections are offered which relate generally to the main research project rather than specifically to each of the three findings chapters.

A particular point raised in Section 3.3.7 involved the concept of power. I made clear attempts to reduce the potential for participants to perceive power as an issue which may have affected recruitment and responses during the interviews. With regard to the occupational therapists, whilst it may be possible that some of the individuals approached were affected by 'being known' to myself as the researcher and/or were concerned their responses may be identifiable and affect their employment, given that 19 occupational therapists in total were recruited this issue did not appear to have affected recruitment overall. Without directly approaching the occupational therapists who chose not to participate in this research, this phenomena will remain unknown.

With regard to the service users and clinicians, I believe that wearing casual clothing rather than a uniform during the interviews positively affected the relationship between the participants and myself. Whilst they were aware my background was within occupational therapy and equipment I had hoped they did not view me as a 'therapist' but as an individual interested in their account and experiences of ADL equipment and occupational therapists. Similarly with regard to the therapists, I believe my choice of casual clothing placed the participants in a position closer to that of a peer rather than

someone who could have been perceived in a position of greater power. Given the volume, depth and level of information provided by the participants in all three subgroups during interview I believe I did achieve the correct balance. I have confidence my fears were allayed by the number of participants recruited and the data they provided. Throughout the research process I paid constant attention to my roles as researcher and as occupational therapist. I used my professional standards and ethical codes (HCPC 2016a; 2016b, COT 2015b, WFOT 2016) to guide my approach and behaviour.

A major concern centres on whether I have 'done justice' to the participants, their data and the process of IPA. To achieve this, I have used a combination of field notes, transcript annotations and supervisory feedback to be as transparent as possible during the practical and writing elements of this research project as a whole. As I now find myself toward the end of the research journey one of the most insightful moments has been the realisation that there is no right or wrong way, provided you stay true to the methodological approach, the methods and the data you collect. Furthermore, I have remained mindful to my role as a researcher and recognised how my experiences and expectations could influence my approach. Whether my prior working relationship with potential participants would influence their choosing to participate and the data they would provide was unfounded. As with other issues, my use of a reflexive journal and field notes enabled me to consider the advantages and disadvantages of this and whether it had in fact occurred.

I recognise I was probably too cautious at times due to my ethical concerns at causing the participants heightened emotions and distress. I believe this was of particular concern as the topic had been discussed during the ethical approval meeting. One challenge throughout the research, but probably as my understanding has grown and developed, relates to the 'little epiphanies' which occurred on how to approach the research and my data, but which slipped away as quickly, and before being able to write or record a legible note. I have lost many ideas, phrases and sentences to this condition. Equally, managing large volumes of data has been difficult. My brain became so 'fogged' by the information attempting to place it appropriately and not repetitively has been problematic. The concept of large amounts of data, selecting excerpts which told the story using the participant's voices was challenging, and clearly a skill to be learnt. The feelings of 'abandonment' this generated when choosing which excerpts to include was difficult.

A major question to ask is whether I would 'do anything different should I repeat the research with a clean slate'?' Regarding the research topic, the response would be 'no'. However, I would alter aspects of the practical side of the research. I would be more aware and mindful of the fluidity of the research process and the trick of using what you have learnt the next time round. For example, I would use A3 rather than A4 paper when transcribing and then printing interviews in combination with more consideration to the layout of columns. In addition, despite reading around the process of research, I repeatedly underestimated the time involved in task elements such as transcribing and analysing the data. The data analysis process is constant and even as I write this sentence, in part I continue to think about the super-ordinate themes and sub-themes and how I would present them differently if given the opportunity. Equally however, recognising that at some point you 'have to stop' actively analysing was challenging, and again I feel as a researcher you want and should do justice to the participants.

In terms of the research aims and objectives, although I may have approached, conducted and presented my findings differently to others I believe I have remained honest. I believe I have maintained the 'occupational therapy lens throughout the process of data collection, analysis and presentation of the findings.

Finally, the process of planning and conducting the research, analysing and writing about the findings, and discussing these with the supervision team and peers has confirmed my passion for occupational therapy practice and ADL equipment. My reflections and discussions have ignited animated responses and raised my frustrations surrounding and influencing the profession to new heights. I am most assuredly in the occupational therapy corner surrounded by the comfort of ADL equipment.

# 7.4 Limitations

Care was taken throughout this research project to ensure a high level of integrity and trustworthiness was maintained. I used a reflexive diary during the research. It includes amongst others, notations relating to the research method and methodology, pre and post interview commentary and notes made during meetings with my supervisory team. It contains a plethora of questions, thoughts, feelings and emotions as they occurred. As outlined in Sections 2.6 and 3.2.3.1 a variety of critical appraisal tools were utilised or adapted to evaluate the literature. Additional efforts included the use of Smith et al's (2009) guidelines for conducting IPA research, the use of which provided supporting

evidence for the effective use of the methodology and trustworthiness of qualitative research. However, despite the careful planning and implementation of thought, in hindsight several limitations can be identified.

Throughout this project I have been mindful of my experience as an occupational therapist who has practiced in the area of equipment assessment and provision and as such the potential influence this may have on my approach to its design and analysis. However, conversely, I am also familiar with the debate within the literature concerning to what degree this influence may enhance a research project rather than jeopardise its objectivity. My use of 'bracketing' within this research is, therefore, not an overt attempt to increase objectivity and thereby reduce bias, but rather an attempt to observe phenomena without the adverse influence of assumptions and preconceived ideas (Finlay 2011).

I maintained a high level of trustworthiness throughout the project. One of the ways I achieved this was by using triangulation techniques such as exploring the perspectives of the participants within the three sub-groups and then across them. I used an audit trail captured using field notes, a reflexive diary and member checking with a member of the supervision team familiar with IPA. These techniques were employed to ensure the research process remained transparent and the findings true to the original transcripts and purpose of the project. In addition, I have met regularly with a fellow PhD student to discuss thoughts and ideas and talk through my rationale and decision-making ideas.

The scope of this research project is limited to the UK. While issues with access to assessment and funding continues to differ between the UK and other European or international states and countries the potential for comparing some elements of this research is nevertheless likely to have been limited. The findings in terms of the impact of equipment upon individuals, whether positive or negative, are however transferrable irrelevant of their source. In the future this could be re-explored/considered in more detail which may offer insight whilst being aware the difference funding may have had.

As a novice researcher, at the commencement of this research journey, I was anxious that I would be insufficiently skilled to undertake research to an acceptable standard. However, in retrospect my background as an occupational therapist used to assessing, observing and interacting with people provided me with a range of transferable skills such as interviewing individuals which included active listening, observational, and organisational skills. However, I also recognise that, despite having this range of skills, my ability to use these effectively in order to elicit phenomenological data to the required depth, and then sufficiently analyse it to the level necessary for IPA was not a given. To mitigate against this, regular supervision guided against this. Equally, these discussions and feedback prevented the insertion of personal and professional preconceptions. Conversely as an occupational therapist, during interventions I am used to offering direction when attempting to clarify the service users position or my perception of the information they are providing. On reflection I believe this was at times evident within the interviews.

As highlighted at the beginning of this chapter (7) the content of the nine studies included in the literature review (Chapter 2) were not particularly helpful in supporting or debating the role of occupational therapists in relation to ADL equipment and the themes raised from the main research project. Whilst this was disappointing it reinforces the knowledge that little research surrounding the topic has been conducted in the UK, particularly in the recent past.

# 7.5 Future research

Although this research is to my knowledge, original in its concept and topic, the need for complementary and additional research is identified. The points below represent points raised within the literature review (Chapter 2) and the three chapters (4, 5 and 6) related to the findings.

- Conduct a systematic review of the literature, national and international, which explores the provision of ADL equipment by occupational therapists and its use by service users. Examine in more detail the content of the research to explore current definitions and identify areas of evidence, if any, and further gaps in the evidence base.
- Consider extending future research to capture the views and experiences of occupational therapy support staff.
- Conduct further qualitative research which explores in greater detail the effect of ADL equipment on service users of all ages, and practitioners' personal and professional identity. This would include further exploration of the literature surrounding identity, discrimination and stereotypical behaviours. Impression management would also be an important element of any future research.
- Further explore local and national experience, understanding and the application of clinical reasoning.

- Further explore the local and national experience of risk, including positive risk taking and risk aversion.
- Expand future research to explore participants' national experiences and perceptions.
- Explore the short and long-term impact and implications of local and national processes on occupational therapists and service users' well-being.
- Conduct a systematic review of the literature which identifies and appraises current equipment specific outcomes. Examine which equipment outcomes are most valued by patients, clinicians, senior management and commissioners. Develop a sensitive measure which can be adapted to service contexts and equipment types. This should incorporate elements of the utility of equipment and the service user's voices to ensure a broad evidence base can be developed.
- Conduct research which explores the understanding and experiences of ADL equipment by other professions. This could combine the use of a survey and interviews to elicit information.
- Revisit the data collected during this research project to highlight areas of local improvement, disseminate and amend processes then audit against them.

As occupational therapists we may instinctively believe that equipment outcomes are both positive and negative. However tacit knowledge lacks the power of robust research and the sensitivity of meaningful outcome measurement now demanded by modern clinical practice. In 1979, Stowe stated "It is a well known fact" (p168) when discussing independence and dependence and how with the latter "life becomes limited" (p168). Whilst this was and remains probable, at the time one could expect the comments were drawn from experience and assumption. Now comments such as this are considered to hold greater weight due to the pooling of clinical knowledge and understanding which is supported by research. Many of the papers included in the literature review in Chapter 2 (Thornely et al 1977, Stowe 1979, Beattie and Caird 1980, Chamberlain et al 1981, Stowe et al 1982) offered the perspective of the authors without the backup or defence of other research or evidence. Equally, while research which focusses on practicalities and functional outcomes has the capacity to offer some insight, that which includes the participant voice is stronger and offers a powerful vector to convey the benefits and shortfalls of ADL equipment and clinical practice. An increase in the use of qualitative research will assist in bridging this gap. Equally however, a review conducted by Michie et al (2004) found a high proportion of research findings and recommendations failed to effect change in clinical practice. As such, it is important as conducting the research is to explore and identify methods by which

research evidence is seen by clinicians and stakeholders alike, and integrated into practice; a point discussed by Adams (2016). Furthermore, Adams (2016) advocates the need for occupational therapy research which is grounded in clinical practice.

### 7.6 Summary

This thesis set out to explore the relationship between occupational therapy and equipment for activities of daily living. The first chapter introduced the rationale and context for this research which included the researcher's personal and professional perspective. A set of definitions focussed on the key concepts of occupational therapy, occupational therapists and equipment. It provided insight into local and national policy and identified the lack of specific guidelines to support decision making around the assessment and provision of ADL equipment.

Chapter 2 reviewed the research literature relevant to occupational therapy practice and the provision and use of ADL equipment within the community. Whilst a large amount of literature was available, very little of this proved pertinent and that which did was found to lack the desired levels of evidence appropriate to current clinical practice. While the literature included in the review approached and sourced information directly from occupational therapists and service users this was found to be quantitative in nature. None of the research sought out the active voice of its participants. The combined information collected from Chapters 1 and 2 formed the basis and main support mechanisms for the main research project. The principal research question and objectives can be found in Sections 1.6 and 1.7 respectively.

The overall aim and principal research question was to explore 'How [do] service users and occupational therapists in the United Kingdom experience equipment for activities of daily living? To achieve this a research methodology able to capture the voices of the participants was necessary. As such a qualitative approach was deemed the most appropriate with IPA selected as the underpinning methodology to collect and analyse the data. Data was collected via face-to-face interviews from a total of 26 participants who formed three separate homogenous sub-groups – clinical leaders, occupational therapists and service users. As introduced in Chapter 1, Section 1.1, the research was viewed through the perspective of occupational therapy practice. The research methodology and methods were discussed in detail in Chapter 3.

Chapters 4, 5 and 6 presented the findings of the three participant sub-groups. The findings in each of the three chapters were structured using the super-ordinate themes and sub-themes which developed during the analysis and writing processes.

Chapter 7 revisited the sub-group findings and explored the collective issues, arising from each sub-group. Care was taken to ensure the homogeneity of the sub-groups was protected. Chapter 7 then considered the overall findings in relation to the extant and wider literature before positioning the overall findings in line with the implications to clinical practice. As identified in Chapter 2, although large volumes of occupational therapy and equipment-based literature exists, little of this relates to or presents a deeper understanding of its merits and drawbacks, particularly that which originates from the users and providers voices. Limitations which may have affected the research project were identified, discussed and where appropriate alternative options are provided. Chapter 8, the final chapter draws together what has been learnt in relation to the principal research question and objectives as outlined in Chapter 1 (Sections 1.6 and 1.7).

#### **Chapter 8: In Conclusion**

Collectively, the research question and associated objectives are fulfilled by the findings of this original research project. In essence, the participants of this main research project and authors of the previously published research indicated 'equipment' is considered an integral element of current and future occupational therapy practice. It is also an integral aspect of occupational therapy and its professional identity. Equally, the concept of ADL equipment has an impact on service user roles and their associated identity. Despite several misgivings, the consensus amongst the participants within this research indicated that equipment provision and use involved empowerment, improving well-being and motivating individuals toward a more positive future. However several misgivings remain including a need for the profession of occupational therapy to better understand its current relationship with ADL equipment and how it wishes this to be perceived in the future.

The experiences of equipment users, occupational therapists and clinical leaders explored through the interview and analysis process has provided a rich source of evidence which supports the continued role of occupational therapy and the provision of ADL equipment, provided there is a clear direction and purpose for its use.

Equally, this research has further highlighted several historic issues for example equipment use and non-use, over prescription and risk eversion which will benefit from further address on a local and national level.

The primary plan following the completion of this thesis is to disseminate its findings locally, nationally and internationally. Locally, this would involve presenting findings to other occupational therapists employed across a range of organisations, managers and clinical leaders, and stakeholders responsible for funding equipment based services. The latter point would include services which assess for and provide ADL equipment (such as community therapy) and those who provide equipment such as the Assisted Living Centre or its equivalent within the local Trust. Nationally and internationally, the findings will be disseminated via a peer reviewed journal and attendance at appropriate conferences. For the majority of the time taken to complete this research two journals stood out as the most predominant options. These were: the British Journal of Occupational Therapy and the Disability and Rehabilitation: Assistive Technology Journal. However, during the process of writing the thesis and reflecting on the literature identified and sourced throughout its commission, the need to consider the

potential of other journals has grown. As such, I now question whether publication in the American, Canadian, Australian or Scandinavian journals would have the potential to reach a wider audience and thereby greater impact. The need to therefore further examine and explore the circulation potential and equally the ease of access to published articles within journals is indicated. The purpose of disseminating the findings of this research would hopefully generate interest in the topic and encourage others to undertake their own research in the subject. This would provide further evidence surrounding occupational therapy, ADL equipment and service user experience; including the positive and any negative issues. A summary of the findings forwarded to local and national policy makers and professional bodies such as the Royal College of Occupational Therapy and the World Federation of Occupational Therapists may well raise additional interest in the need for further and future research.

Further to the completion and publication of the findings of this research project, 'this' feels like the start of more to come. There is more I would like to find out and say about equipment, particularly surrounding the voices of the providers and users. To support 'what comes next', a systematic review of the national and international literature would identify all research pertinent to the topic of occupational therapy and ADL equipment. Expanding the search and inclusion criteria to include occupational therapy services rather than occupational therapists exclusively may enhance the findings of research in this area. Equally, the inclusion of research involving occupational therapy and physiotherapy practice may provide an even greater insight into the use and non-use of ADL equipment. Likewise, capturing the voices of support workers, children and other users of ADL equipment will offer additional insight and perspective. Moreover, understanding the perception of other professionals' understanding of ADL equipment and the relationship between it and occupational therapy may assist with informing colleagues of their wider clinical role whilst also raising its profile. Highlighting the intricacies and complexity of ADL equipment assessment and provision may also be forthcoming.

Whilst there may not be an immediate change in practice, this and other research will provide a starting point. As the service user's voice and others are raised they will over time become louder and less easy to ignore.

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# Appendices 1 – York St John University Approval Letter



Faculty of Health and Life Sciences Lord Mayor's Walk YORK YO31 7EX Tel: (01904) 876734 Fax: (01904) 876500

Nathalie Noret Chair of Faculty of Health & Life Sciences Research Ethics Committee Direct Line 876311 E-mail: n.noret@yorksj.ac.uk

14 April 2016

Dear Jenny

**RE:** Service users' and providers' experiences of equipment provision in occupational therapy

REF: 79011002\_Harrand\_23022016

The research ethics committee has approved, without reservation, the above research ethics submission of date of submission 23 February 2016.

Yours sincerely

N. NOHRA

# Appendices 2 – Health Research Authority Approval Letter



Miss Jennifer Harrand 14 Berkeley Road Cleethorpes DN350NX Email: hra.approval@nhs.net

27 January 2017

Dear Jenny

# Letter of HRA Approval Study title: Service users' and providers' experiences of equipment provision in occupational therapy IRAS project ID: 203862 REC reference: 16/YH/0428 Sponsor York St John University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read** *Appendix B* **carefully**, in particular the following sections:

- Participating NHS organisations in England this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- Confirmation of capacity and capability this confirms whether or not each type of participating

NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

• Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

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and further information about working with the research management function for each organisation can be accessed from <u>www.hra.nhs.uk/hra-approval</u>.

#### Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
  - B Summary of HRA assessment

#### After HRA Approval

The document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the <u>HRA website</u>, and emailed to <u>hra.amendments@nhs.net</u>.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the <u>HRA website</u>.

#### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <u>http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/</u>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at <u>hra.approval@nhs.net</u>.

Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

# **HRA** Training

We are pleased to welcome researchers and research management staff at our training days – see details at <u>http://www.hra.nhs.uk/hra-training/</u>

Your IRAS project ID is **203862**. Please quote this on all correspondence.

Yours sincerely

Isobel Lyle | Senior Assessor **Health Research Authority** Room 002, TEDCO Business Centre, Rolling Mill Rd, Jarrow NE32 3DT <u>Hra.approval@nhs.net</u> or <u>Isobel.lyle@nhs.net</u> T: 0207 972 2496 www.hra.nhs.uk

# Copy to: Dr Stephen Gibson, Sponsor contact, York University Debrah Bates, R&D contact, Northern Lincolnshire and Goole NHS Foundation Trust

# **Appendix A - List of Documents**

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Contract/Study Agreement [Statement of Activities]	1	26 January
		2017

	r	
Covering letter on headed paper [cover letter one ]	one	01 September 2016
Covering letter on headed paper		06 November 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [2015 08 12 Amended list of premises]	two	27 July 2016
Interview schedules or topic guides for participants [leader manager interview schedule ]	two	02 September 2016
Interview schedules or topic guides for participants [clinician interview schedule ]	two	02 September 2016
Interview schedules or topic guides for participants [patient interview schedule ]	two	02 September 2016
IRAS Checklist XML [Checklist_17112016]		17 November 2016
Letter from sponsor [approval letter one ]	one	14 April 2016
Other [Schedule of Events]	1	26 January 2017
Other [cv - dr jane cronin-davis one ]	one	14 June 2016
Participant consent form [participant consent form ]	four	17 November 2016
Participant information sheet (PIS) [leader manager information ]	two	05 September 2016
Participant information sheet (PIS) [therapist information sheet ]	two	05 September 2016
Participant information sheet (PIS) [patient participant information sheet (PIS)]	three	16 October 2016
REC Application Form [REC_Form_01092016]		01 September 2016
Research protocol or project proposal [proposal ]	two	02 September 2016
Response to Additional Conditions Met		17 November 2016
Summary CV for Chief Investigator (CI) [cv - jh one]	one	14 June 2016
Summary CV for supervisor (student research) [cv - dr stephen gibson one]	one	16 June 2016
203862 16.YH.0428 Favourable_opinion_on_further_information		16 November 2016

# Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

# For information on how the sponsor should be working with participating NHS organisations in

England, please refer to the, participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix. The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Dr Stephen Gibson Tel: 01904876444

Email: <u>s.gibson@yorksj.ac.uk</u>

# HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities has been provided. The sponsor is not requesting and does not expect any other site agreement.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.3	Financial arrangements assessed	Yes	No funding is being provided to the participating NHS organization (source: Statement of Activities).

5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	<ul> <li>NHS Research</li> <li>Ethics</li> <li>Committee</li> <li>favourable opinion</li> <li>received for</li> <li>applicable studies</li> </ul>	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

# Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is only one 'site-type' undertaking the research activity

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at <u>hra.approval@nhs.net</u>. The HRA will work with these organisations to achieve a consistent approach

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different. to information provision.

# **Confirmation of Capacity and Capability**

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England (will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The <u>Assessing, Arranging, and Confirming</u> document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

# **Principal Investigator Suitability**

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The Sponsor has advised that a Chief Investigator is in place at the NHS organisation. This is an educational study and the Chief Investigator is the student. If the study should be extended to include additional sites, the Sponsor will be required to restate the position with regard to whether a PI, LC or neither should be in place at those additional sites.

GCP training is <u>not</u> a generic training expectation, in line with the <u>HRA statement on</u> <u>training expectations</u>.

# HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the preengagement checks that should and should not be undertaken An Honorary Research contract for the Consent research activity listed in A18 or A19 of the IRAS application form if undertaken at NHS sites by researchers not employed by that organisation would be expected on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation or pre-engagement checks letter (if NHS employed).

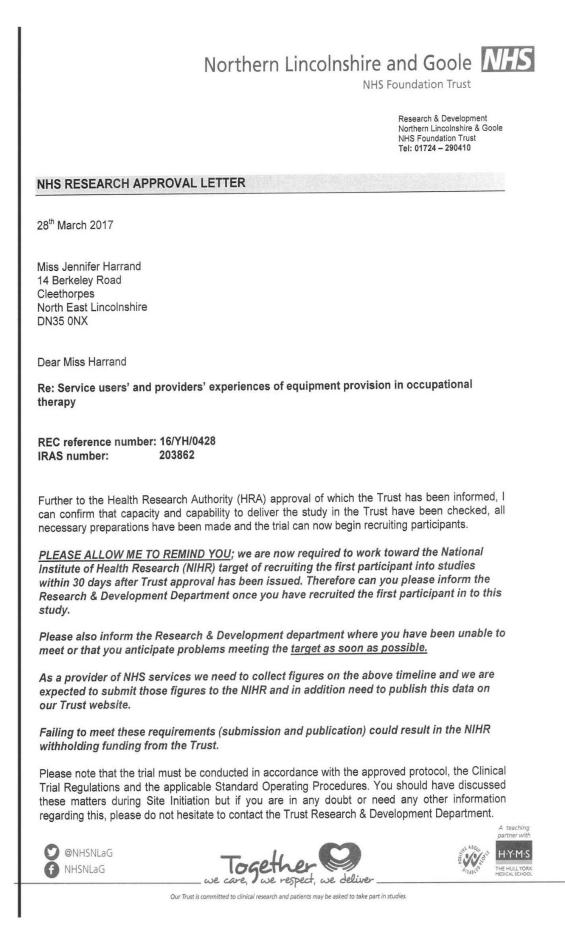
These should confirm enhanced DBS checks, including appropriate barred list checks and occupational health clearance.

# Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

□ The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

#### Appendices 3 – National Health Service Approval Letter



THE FINAL LIST OF DOCUMENTS APPROVED BY THE TRUST ARE AS FOLLOWS:

DOCUMENT	VERSION	DATE
Participant consent form	4	17/11/2016
Protocol	2	02/09/2016
P.I.S.: leader manager information	2	05/09/2016
P.I.S.: therapist information sheet	2	05/09/2016
P.I.S.: patient participant information sheet (PIS)	3	16/10/2016
Leader manager interview schedule	2	02/09/2016
Patient interview schedule	2	02/09/2016
Clinician interview schedule	2	02/09/2016

May I wish you every success with the trial.

Kind regards

de. fead

Mrs Marion Hood Research Management and Governance Manager Northern Lincolnshire & Goole NHS Foundation Trust

#### Appendices 4 – Participant Information Form



School of Health Sciences Lord Mayor's Walk YORK YO31 7EX Tel: (01904) 876734 Fax: (01904) 876500

# Service user's and provider's experiences of equipment provision in occupational

# <u>therapy</u>

#### **Patient Participant Information Sheet**

You have recently been seen and assessed by an occupational therapist who has provided you with some equipment for daily living activities. Examples of this equipment may include items for your toilet, bath or shower, kitchen or to assist you with your mobility or transfers from one place to another. I would like to invite you to take part in a research study to explore your experiences of the occupational therapy assessment and your use of the equipment provided. Before deciding whether to take part, please take the opportunity and time to read and consider the following information; you can discuss this information leaflet with your family and friends if it will assist you in making a decision.

#### Purpose of the study

I am currently in the process of completing a Philosophy Doctorate at York St John University. My specific area of interest is the assessment and provision of equipment for activities of daily living by occupational therapists.

As an occupational therapist I have provided patients, such as yourself, with equipment for their activities of daily living. I have not however had the opportunity to find out whether the equipment I have provided has made any difference to my patients ability to carry out activities and the impact this may have had for example on their quality of life. I am also interested in exploring how the assessment process may have affected which types of equipment patients are provided with. I am also interested in what other occupational therapists and their managers think about the subject.

The study will explore equipment use and provision from the point of view of up to 10 patients, 10 occupational therapists and their managers (10).

#### Do I have to take part I the study?

**No**, it is up to you to decide whether or not to take part in the study. Use the information provided and any discussions you may have with your family or friends to assist you in making a decision. You can also contact me directly should you require any additional information that may assist you to make a decision.

#### Taking part in the study

If you agree to take part you will be interviewed by me at a time and place convenient to you. If the interview were to take place in your own, a family members or friends home you will be given the opportunity to access refreshments. Similarly, if you choose to be interviewed elsewhere such as in a public place or the hospital site the opportunity to access refreshments will also be ensured.

The interview will involve you discussing your recent experiences of an occupational therapy assessment, the equipment you were provided with and the impact this may have had on you. The interview would take about one hour. You can choose not to respond to specific questions during the interview. You can also withdraw from the interview without having to provide a reason.

You may also withdraw from the study up to two weeks following your interview without having to provide a reason. My contact details can be found in the additional information section.

The interview would be recorded using a hand held mobile recording device which would then be typed up (transcribed) by me word for word. I would then analyse or explore the transcript along with any others to identify common themes.

The findings of the study will be included in my research report and may also be published in professional journals or presented at conferences, seminars or lectures. The report will include some extracts of the transcripts to support my analysis.

Please note that any information used in the report, publications, conferences, lectures or seminars will not identify you – your contribution will remain confidential and anonymous. All information will also be stored securely. You will be offered the opportunity to receive a copy of your interview transcript and the final thesis.

Please take at least 24 hours to consider whether you would like to take part in the study.

#### Benefits of taking part in the study

It is hoped the information gathered from this study will help to guide future occupational therapy assessments and provide feedback relating to the use of equipment (whether good or bad).

#### Are there any disadvantages of taking part in the study?

Taking part in this study will not affect your future contact with occupational therapists or prevent you from being provided with equipment identified as appropriate to your needs.

There is a chance that you may become upset during the interview due to the topics under discussion, for example your health and the difficulties you face. If this occurs, you will be able to pause or stop the interview. Information and contact details for supporting organisations will be available should you feel you need them.

#### Additional information

If you require any additional information or have any questions please contact me by telephone on 01904 876444 or by email as follows j.harrand@yorksj.ac.uk

#### Agreement to take part in the study

If you agree to take part in the study you will need to sign and date the shaded Informed Consent to Arrange an Interview Section at the bottom of this page and return the top copy to me in the envelope provided. Completion of this section indicates that you agree for me to contact you to arrange an interview. Once I receive your completed form I will contact you to arrange an interview at a date and time convenient to you. Prior to the start of the interview, I will answer any additional questions you may have and ask you to complete a Consent to Interview Form that I will bring with me.

Informed Consent to Arrange an Interview: please provide the following information.

Your Name: Your Signature: Your Address: Your Telephone Number:

#### Yours Sincerely

#### Jenny Harrand

Jenny Harrand | Senior Lecturer | York St John University, Lord Mayor's Walk, York, YO31 7EX | 01904 876444 | <u>i.harrand@yorksj,ac,uk</u>

Top copy to be returned to Jenny Harrand in the envelope provided. Patient to retain the bottom copy for their records.

# Appendices 5 – Consent Form



School of Health Sciences Lord Mayor's Walk YORK YO31 7EX Tel: (01904) 876734 Fax: (01904) 876500

# **CONSENT to INTERVIEW FORM**

**Title of Project**: Service user's and provider's experiences of equipment provision in occupational therapy

Name of Researcher: Jenny Harrand

Please initial box

1. I confirm that I have read the information sheet dated .....

(version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to

withdraw at any time without giving any reason, without my medical care or legal rights being affected.

- 3. I understand that the information collected about me may be used to support other research in the future
- 4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 5. I agree to take part in the above study.

Name of Participant

Name of Person (Taking consent) Date

Date

Signature



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Signature

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Appendices 6 – Example - Transcript, commentary and sub-themes

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regular basis and motivates the child as well erm so err what else probably and would get some error (sections) from the child when so err what else probably and work much server (sections) with me her, involved or out with the rep and i would observe the the (child's behaviour) and and the interfinded go out with the rep and i would observe the the (child's behaviour) and and the interfinded go out with the rep and i would observe the the (child's behaviour) and and the interfinded go out with the rep and i would observe the the (child's behaviour) and and the interfinded go out with the rep and i would observe the the (child's behaviour) and and the interfinded and the interfinded from my observations and once they can start telling the we get them to do a thumbs from my observations and once they can start telling the we get them to do a thumbs from my observations and once they can start telling the well and the well and the the from my observations and the interfield and the	so err what else probably and the new low low here is observaling a first time I wouldn't have the includence of the terrel of corners of the here of	eaupment is a use befor they are able 6 communicate use of the hond "voice" ercpected use of the hond "voice" part of our values - it's what we do to succept the organization to there a sucception that it has the in a	then acted y don't the child lancthes?
	ar basis and motivates the child as well erm so err what else probably and laget some err feedback from the child when so err what else probably and laget some err feedback from the child when so err with the rep and I would it have leve of equipment probably with me then I would go out with the rep and I would in the rep and I would in the the child's <u>behaviour</u> and then their mood and their erm tolerance is much so I'd get some I'd err observe how they responding to it and how they to the they look comfortable or if they look whatever so I'd I'd I'd my observations and once they can start telling me we get them to do a thumbs is a fell me how they like it when they're able to definitely they have to be they are in the view of the they look whatever so I'd I'd I'd my observations and once they can start telling me we get them to do a thumbs is a fell me how they like it when they're able to definitely they have to be they are in the to be they are in the solve they in the to be they able to be they have to be they are the to be the to be the to be they are the to be the to be the to be they are the to be they are the to be to be the to be the to	it we our solutions and soluti	305 / Jon 318 to 322) 7 the the voice of the child has been it's you know that's is been recorded that would always happen anyway se but it's now a way of being able to the information at the minute erm and outcome web it it indicate we have to

#### Appendices 7 – Collation of group super-ordinate themes/sub-themes

Red font - key words, green highlight - discarded

Using transcript extracts to highlight themes and super-ordinate themes – case by case – step 4 (Smith et al 2009, p99)

#### The individual

#### person centred

**Bobby** – line 29-35 – it could be erm to facilitate a need of something personal for them what they would like to do like even it's a pen grip or if they want to carry on writing but it might be really adapted and with facilitation so there's lots of kinds of things from chairs to a toilet commode to a pen grip to err err splint for the arm the foot the knee all kinds of different things we provide

**Bobby** – **line 55-58** – whether it's gonna be more long term whether it's slow recovery or whether it's the potential is is hitting every mark every week erm as everybody's different so erm its very individualised it's very personalised to the person

**Bobby – line 105-108** – it's very individualised looking at the person and at their abilities looking at their risk their cognition whether what they can cope with erm and how we can manage that

**Bobby – line 131-139** – it can be anything from err social things it can be thumb thimbles err it might be pen grips it could be erm ... things for erm using ou err err in the house and then outdoors it might also be for carrying meals as well like a four wheeled walker where you'd you'd put drinks on it as well so they can be multipurpose but we do see it it's the personalised thing err err err individual plan cause we're looking at their err abilities to err ... their their interests and their hobbies of their occupations what they do at home is vital to keep them going

**Bobby – line 145-155** – we all have occupations how how you know we're all very different and every patient walks through the door is very different to what they do and I I had a patient the other day who the family laughed where I said about him joining in participating in with meals and they turned round and said he's never he's never been in the kitchen he wouldn't know how to make a meal and even at a buffet he's never served he's never gone and picked the food himself it's something he's never done so we approached that would he be interested in that and he was like no [both laughing] so so that was quite clear

**Bobby – line 155-161 – it's really getting to know** your patient of what what what they do an rea and getting to know the family and making sure that they're involved as well because the you you know when people go home it's not just about a care support it's not just about the equipment it's about your whole community and it's accessing that community it it's somebodies health and well-being erm goes beside each other

**Bobby – line 199-205** - we've really concentrated on that and he's really really taken it on board and he's really happy he's able to manage the majority of it himself and I am certain he knows that wor because we're working on it he knows that he's very he's the the trust is there and we're building on what we're working towards that goal so it's keeping that person motivated and keeping going to achieve what they need to achieve

**Bobby – line 359-363** – if you can give a piece of equipment what would do two things but bearing in mind there's lots of different skills like I mentioned with the child there's the different activities mean different things for that child for his development and for the family so sometimes you have to look at the whole picture

**Bobby** – **line 419-424** – we also get the people what are using it so we've boxed clever this time we've actually got a patient to use it we've asked the staff our err carers how they feel about it and how how eas easy it was to use compared to our other chairs so that's what we've been doing at the minute we've been boxing clever

**Bobby – line 676-688** – the only thing I would always like to see in the future is for seeing the person as an individual person and not as erm not everybody's going to be erm seen to tick every box on on a form ... because everybody's an individual and we don't just fit into set boxes and we just need to keep that reminding when we set up services that it's not just it can't be just a tick box exercise cause we don't all fit in boxes [......] because when we when we look at eligibility for criteria's and different areas for equipment that erm not everybody will fit into set boxes

**Bobby** – line 709-711 – what I'm saying not everybody fits into that box and it's not always to be rigid sometimes there's a great

Bobby