Care in my own home: Elders' accounts of receiving domiciliary care for the first time

BETHANY MANNING

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ABSTRACT

Background: In England, over 700,000 people are supported to remain living in their own homes by receiving domiciliary care. The existing UK research focuses primarily on the quality and cost-effectiveness of care. Receiving care for the first time can be a significant change to daily life, yet there is a lack of research exploring elders' experiences of first receiving domiciliary care.

Aim: To explore elders' accounts of receiving domiciliary care for the first time.

Methodology: A critical realist approach was adopted. Individual semi-structured interviews took place with ten elders (aged 76-95) receiving domiciliary care in Southeast England. Interview transcripts were analysed using reflexive thematic analysis.

Analysis: Two overarching themes were generated. The first overarching theme, 'A new, important relationship', comprises the themes: 'Carers are like friends' and 'Support to continue with life'. The second overarching theme, 'Who am I now? Changing view of oneself', contains the themes: 'Struggling to accept the need for help' and 'Lost parts of the self'.

Conclusions: The findings suggest that receiving domiciliary care for the first time is a significant life event, which prompts realisation of one's advancing age and a changing view of the self. A friendship-like relationship with carers promotes elders' psychological well-being and supports elders to accept care into their lives. The findings highlight the considerable psychosocial value of domiciliary care. Potential implications include contributing to training for carers and health professionals supporting elders during the transition into receiving care.

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LIST OF ABBREVIATIONS

UK	United Kingdom
NHS	National Health Service
ADL	Activity of Daily Living
ONS	Office for National Statistics
NAO	National Audit Office
ICS	Integrated Care System
CQC	Care Quality Commission
EHRC	Equality & Human Rights Commission
RAM	Roy Adaptation Model
CLCT	Caring Life-Course Theory
TA	Thematic Analysis
UEL	University of East London
BPS	British Psychological Society

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1. INTRODUCTION

1.1. Chapter Overview

The chapter opens with an introduction to my personal context and an outline of the key terminology. This is followed by an exploration of the historical and socio-cultural context of the lives of elders in the UK and an overview of the care system. Theory relevant to domiciliary care and a scoping review of the literature are presented. The chapter ends by describing the rationale for the current study and presenting the research questions.

1.2. Personal Context

The researcher's influence on their studies exists from the outset, from forming initial questions to selecting participants, analysing findings, and choosing how and where findings are presented (Hertz, 1997). In qualitative research, the subjectivity of the researcher can be considered an opportunity, rather than a problem to overcome (Finlay, 2002). I am aware of the significant power I hold as a researcher. By situating myself below, I hope to acknowledge my own position and my role in the co-construction of knowledge throughout the research process.

I am a White British, cisgender female in my late twenties. I have grown up with a close bond with one particular elder in my life: my Nan. She is in her eighties and lives alone with support from domiciliary carers and family members, including myself. The struggle to find good quality care for Nan, as well as the wonderful times of support, compassion and fun I have witnessed between Nan and her carers, have undoubtedly informed my interest in this area.

During my work in stroke services, I encountered elders daily who were facing the need to have care at home on their discharge from hospital. These elders often reported having little choice and little-to-no time to prepare for this significant change. I witnessed how, often very suddenly and unexpectedly, elders found themselves dependent on the support of others to get out of bed or access the bathroom.

These experiences have left me with many questions, which have informed and developed with this research. For example, how does it feel to go from independence to relative dependence? What does it mean to be at the point in your life when you need care? Are both physical and psychological needs cared for? How can health professionals support elders, their carers, and families as they navigate this change? These are the types of questions I will explore.

1.3. Key Terminology

This section outlines and explains the choice of the key terminology used throughout this thesis.

1.3.1. Elder

Defining an “older person” is challenging and subjective. Many people in their later years would not describe themselves as old (Furstenberg, 1989; Hurd, 1999). Historically, the definition of old age has been linked to the age at which one retires and/or qualifies for a State Pension, yet difficulties in classifying the appropriate age for this have long existed (Roebuck, 1979). NHS England (n.d.b) generally considers an older person to be someone over the age of 65, yet acknowledges that age is neither a reliable predictor of health nor the level of support a person requires. To maximise the clinical relevance and utility of the research findings, the current study adopts these criteria employed by NHS England for recruitment and descriptive purposes. These criteria have been applied in a flexible nature, to reflect that there is no clearly defined point at which one becomes “old”.

The terms used to describe people in their later years vary across services and settings. For example, Age UK (n.d.b) refers to “older people”, whereas “older adult” is the term used in NHS mental health services (NHS England, n.d.a). Although surveys of people’s preferences do exist (e.g., Barbato & Feezel, 1987), there appears to be a lack of recent research, making it difficult to select a descriptor on this basis. Some authors have recommended referring to people as “older”, rather than “aged” or “elderly”, to reduce associations with frailty (Avers et al., 2011; Falconer & O’Neill, 2007; Quinlan & O’Neill, 2008). In 1995, the United Nations advocated for “older” to be the descriptor used (United Nations Committee on Economic, Social and Cultural Rights, 1995). More recently, terms such as “older adult” or “older person” have been said to imply comparison and considered to be othering on the basis of age (Castro Romero, 2015).

The current study utilises the term *elder*, which recent publications suggest is a respectful way of referring to this age group, acknowledging the wisdom and contributions of those who have lived longer (Bowman & Lim, 2021; Castro Romero, 2015).

1.3.2. Domiciliary Care

The terms *homecare* and *domiciliary care* are often employed interchangeably to refer to professional care provided to individuals in their own homes. Domiciliary care providers employ paid care staff, often referred to as carers, care assistants or care workers, to support individuals with activities of daily living (ADLs) in their own homes. ADLs may include getting washed and dressed, preparing meals, and taking medication. These services can be distinguished from “home help” services, which offer support with domestic tasks, such as cleaning, laundry and gardening.

The current study utilises the term *domiciliary care* to refer to formal care provision within the adult social care sector and not to refer to medical care delivered at home, such as district nursing, or care delivered by family members or friends (“informal” care). The term *domiciliary care* was chosen over *homecare*, to clearly distinguish from the other forms of care provided at home outlined above, which may be referred to as “home care” in the academic literature.

1.4. Old Age

This section outlines historical and socio-cultural factors influencing the lives of elders in the UK, including societal perceptions of old age and the impacts of ageism.

1.4.1. Historical and Socio-Cultural Context

Across the world, people are living longer (World Health Organization, 2022). Population ageing in the UK is considered to be the result of decreasing mortality and fertility rates, following medical advances, changes in family structures, and increased educational opportunities and employment rates over time (Government Office for Science, 2016).

The care of elders in the UK has changed as the population has aged. The hospitals of the eighteenth and nineteenth centuries would rarely admit older patients and diseases associated with older age did not feature in medical education (Denham, 2016). In the early 20th century, care of elders became regarded as a responsibility of the State. Following the birth of the NHS, hospital admission, rehabilitation and treatment of ill health in elders increased, and community services emerged (Denham, 2016). There are now over 11 million people aged 65 and over in the UK (Office for National Statistics [ONS], 2022c). Advancing age is associated with greater healthcare and social care costs (Government Office for Science, 2016) and the pressure on health spending is set to continue to grow as the population ages (Licchetta & Stelmach, 2016).

1.4.1.1. Societal perceptions of old age

In the UK, the dominant societal narratives surrounding old age relate to decline and loss, such as of mental and physical health, cognitive ability and independence (Centre for Ageing Better, 2021). Media discourses have been found to position elders as a distinct demographic group, outside of mainstream society (Fealy et al., 2012). Stereotypes of declining competence with age are common in Western societies (Abrams, 2005; Abrams, Vauclair, et al., 2011;

Cuddy et al., 2005). Some positive associations with elders exist, such as perceptions of elders as wise, knowledgeable and generous (Hummert et al., 1994), and warm and friendly (Abrams & Houston, 2006; Cuddy et al., 2005; Fiske et al., 2002).

Dependency on others is generally negatively perceived (van der Weele et al., 2021), which may reflect neoliberal attitudes towards individual responsibility and the valuing of independence and autonomy within Western societies (Peacock et al., 2014). Discourses surrounding the UK's ageing population include a "challenge for the NHS" (G. Hughes, 2017, p. 81) and a "burden for the twenty-first century" (p. 80), because of the demands placed on limited public resources.

Societal perceptions of elders can impact service provision, the quality of services elders receive, and elders' well-being (Hoban et al., 2013). For example, associating old age with decline may encourage overprotective caring which reduces elders' skills. UK elders have reported feeling that society views them as a burden and experiencing low self-esteem (Hoban et al., 2013). Elders have also shared feeling reluctant to access services which stereotype older people, increasing their isolation (Hoban et al., 2013). Plath (2008) argues that the dependency and marginalisation of elders are not natural parts of the ageing process, but occur because of socially constructed views of elders, maintained by ageism.

1.4.1.2. Ageism and care

Ageism has been reported to be the most common form of discrimination in the UK (Abrams, Russell, et al., 2011). The World Health Organization (2021) defines ageism as "when age is used to categorize and divide people in ways that lead to harm, disadvantage and injustice" (p. 15). Age UK (n.d.a) defines ageism as "discrimination or unfair treatment based on a person's age" (para. 1).

It is important to consider ageism in relation to care because ageism is likely to impact care-related policy, service provision, and elders' individual care experiences. There is a wealth of evidence demonstrating the existence of ageism within health and social care (Clark et al., 2009; Lievesley et al., 2009a, 2009b; Williams et al., 2003), often linked to the stereotypes of illness or incompetence outlined above. For example, social care services have been said to provide more restricted support to elders compared to younger people, such as a lack of support with social activities or accessing the community (Clark et al., 2009). These differences have been linked to unequal funding between services for elders and younger adults and an expectation that elders accept an inferior quality of life compared to younger people (Clark et al., 2009). The literature identifies how ageism intersects with other forms of discrimination, such as sexism and racism (Abrams, 2005; Williams et al., 2003).

The recent Covid-19 pandemic has been called a “focusing event” (Reynolds, 2020, p. 499), which highlighted the impacts and prevalence of ageism within UK society. Reference to age and ill health dominated the risk communications to the public, with elders portrayed as a vulnerable group. Discussions about rationing medical resources on the basis of age were widespread (Reynolds, 2020). Deaths involving Covid-19 were consistently highest for those aged 85 and over, throughout the pandemic (ONS, 2022b), and the government’s management of Covid-19 in care homes was widely condemned (Gordon et al., 2020; Hinsliff-Smith et al., 2020).

Poverty among elders has been linked to ageism within UK society (Walker, 1980). For example, the tendency to devalue the worth of elders may infiltrate policy decisions (Walker, 1980). In the UK, 2.1 million elders live in poverty, equating to approximately 18% of elders receiving a pension (Age UK, 2021). Living in poverty both restricts access to care services and increases dependency on care because of illness and disability (Walker, 1980).

1.5. Care of Elders

1.5.1. Current Context

As the UK population ages, the demand for social care services continues to increase (Walker, 2018). The number of elders needing care is expected to reach nearly 1.2 million by 2040 (Age UK, 2019). Economic instability and the current cost-of-living crisis are contributing to the increased level of need (Association of Directors of Adult Social Services [ADASS], 2022). Rising demand is problematic as it outstrips the capacity of care services, leading to poorer quality of care and negatively impacting elders' experiences (ADASS, 2022).

1.5.1.1. Care settings

The adult social care sector provides both short-term and long-term care. Short-term care includes time-limited support, such as reablement services, aiming to maximise independence and reduce the need for long-term support (NHS Digital, 2022). For example, care may be required short-term after a hospital admission or surgical procedure. Long-term care includes nursing, residential and community care (domiciliary care and supported living). At the end of March 2022, 62% of long-term care recipients aged 65 and over were receiving community care, 26.3% were living in residential care settings, and 11.7% were receiving nursing care (NHS Digital, 2022).

In the UK, the majority of care for elders is provided informally by family and friends (National Audit Office [NAO], 2018). This trend for informal caring may be associated with ageism and the devaluing of elders in UK society. For example, elders may be reluctant to access formal care because of concerns about care quality or being seen as dependent. Alternatively, elders may be unable to afford the hours of care that they feel they need, and hence rely on family and friends to provide additional support (e.g., with personal care). Since the Covid-19 pandemic, the number of informal carers and hours of informal care provided have increased, believed to be partially owing to the closures of local services (Carers UK, 2020).

Care systems for elders vary across the world and there are significant political and cultural differences in how ageing and care are viewed (The Lancet, 2014). Within Europe alone, there is wide variation, with informal care being the norm in countries such as Greece, Bulgaria and Romania (Genet et al., 2012). In contrast, in Scandinavian countries, local authorities are legally responsible for care provision and much less informal care takes place (Genet et al., 2012). These differences may limit the direct transferability of research into care across countries, yet provide opportunities for politicians and policymakers to learn from international practices. For example, Norway’s public sector model of care has been praised for delivering equitable care, personalised to elders’ level of need rather than financial means (Gupta, 2013). Norwegian elders have reported trust in state provision of services and general enjoyment of life and ageing (Granerud et al., 2017). This finding suggests that cultural variations in care provision may subsequently impact elders’ well-being.

1.5.1.2. Reasons for care

Experiencing difficulties with ADLs, such as bathing, feeding and walking, becomes more common with age (Age UK, 2019). Fifteen percent of elders aged 65 to 69 have difficulties with one or more ADLs. By the age of 85 and over, one in three people will require support with ADLs (Age UK, 2019). An estimated 1.4 million elders have unmet care needs, including elders receiving no care at all or care which is insufficient to meet their needs (Age UK, 2018a). These elders may experience diminished quality of life, with unmet needs likely to have negative implications for physical and mental health.

The primary reason for short-term care is typically physical support, related to mobility difficulties, whereas the reasons for long-term care are generally more varied (NHS Digital, 2022). As Figure 1 presents, physical support remains the primary reason for care for 74.2% of elders accessing long-term care, followed by support for memory and cognitive needs (13.0%), mental health support (6.3%), learning disability support (3.5%), social support (1.6%) and sensory support (1.4%) (NHS Digital, 2022).

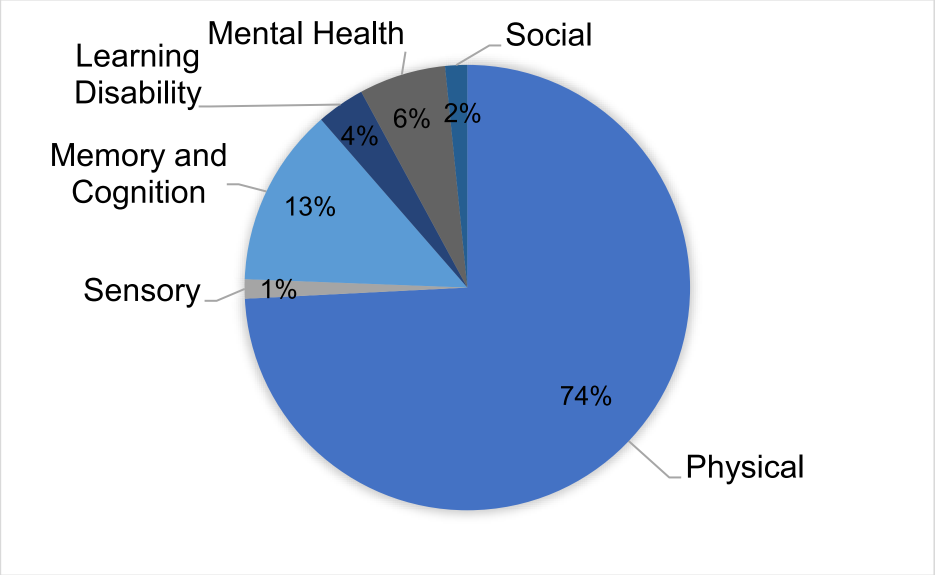

Figure 1

Primary Support Reasons for Long-Term Care for Adults Aged 65 and Over

Note. Data are from "Adult Social Care Activity and Finance Report, England, 2021-22" by NHS Digital, 2022, https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22/long-term-care#primary-support-reason-and-long-term-care. Copyright 2022 by NHS Digital.

Although this literature reports the primary reason for care, many elders receive care for multiple reasons. For example, because declining physical health can impact emotional well-being (Andrew et al., 2012; Keyes, 2005), elders may have both physical and emotional support needs. However, stretched care services may prioritise physical care over emotional support (Gethin-Jones, 2012).

The number of people requiring social care support with mental health needs has increased since the Covid-19 pandemic (ADASS, 2022). For some elders, mental health needs will be the primary reason for requiring care (NHS Digital, 2022). Care staff have previously described feeling ill-equipped and undertrained to respond to mental health difficulties (Secker & Hill, 2002), yet there appears to be limited recent research into this. However, these findings suggest a potential role for clinical psychologists in providing consultation and training to care staff.

Elders may access care for social support and to reduce loneliness (NHS Digital, 2022). Elders can experience loneliness when their circumstances deny them the relationships they desire (Age UK, 2018b). For example, elders may struggle to participate in their local communities because of limited access to transport or lacking someone to accompany them. As outlined above (1.4.), ageism and negative societal perceptions of elders may impact both the services available and elders' confidence to access them. Loneliness is associated with poor physical and mental health outcomes (Crewdson, 2016), which could further increase demand for care. Carers are well placed to identify and reduce loneliness, such as by providing meaningful social interaction and signposting to local social activities (Age UK, 2018b). However, carers may lack the ability to do so because of service pressures, and other barriers to activities (e.g., access) would remain.

1.5.1.3. Political and legislative context

In September 2021, the UK Government announced plans to reform adult social care in England (HM Government, 2021). These plans included a cap on lifetime personal care spending per person and an extended means test, lowering the thresholds at which people would be eligible for financial contributions from the local authority towards their care. Proposed implementation was from October 2023, however, a two-year delay was announced in November 2022 (UK Parliament, 2022). The delay is symbolic of the continued deprioritising of elders and the care sector. Care bodies and charities have highlighted the risk that more services will close during this time, leaving more elders with insufficient support (Samuel, 2022).

In December 2021, the UK Government published a White Paper called “People at the Heart of Care” (Department of Health and Social Care, 2021), which outlined a 10-year vision for adult social care reform. The commitments included identifying unpaid carers and greater investment in workforce training. Although welcomed, the White Paper has been criticised by social care organisations for lacking detail and funding and failing to address the urgent needs of the sector (ADASS, 2021).

The *Health and Care Act 2022* amended the *Care Act 2014* so that the contributions paid by local authorities towards care costs would not count towards the individual's lifetime cap. Once the reforms are implemented, more elders are expected to be eligible for financial support towards their care costs (HM Government, 2021). However, these funding changes do not guarantee that elders will experience higher quality care. Integrated Care Systems (ICSs) were created under the *Health and Care Act 2022* to progress collaborative working. ICSs bring together healthcare providers, NHS commissioners, local authorities and local partners to discuss and plan services to fit the needs of local populations (The King's Fund, 2022). Care professionals have reported desiring more collaboration with healthcare services (Hall et al., 2017). However, as ICSs are new developments, the long-term impacts remain to be seen.

1.6. Domiciliary Care for Elders

This section outlines the context of domiciliary care for elders within the UK and provides an overview of relevant theory and existing research.

1.6.1. Current Context

Domiciliary care has been described as the "front line" of adult social care delivery (Jefferson et al., 2018, p. 2). It is estimated that 714,000 people in England are receiving domiciliary care (NAO, 2021). This number greatly outstrips the number of people living in care homes in England, which was estimated at 360,792 in February 2022 (ONS, 2022a), demonstrating the significance of the domiciliary care sector to the care of elders in England.

For many adults, domiciliary care will be their first experience of receiving formal care, as guidance suggests alternative methods of care provision should be fully considered before admission to residential or nursing care (NHS England, 2014). "Ageing in place", remaining in one's own home in older age, is a key part of UK government policy in relation to cost-saving and the ageing population (Sixsmith & Sixsmith, 2008, p. 219). With the domiciliary care sector facing ongoing economic challenges, it is increasingly important to understand elders' experiences of care within this climate.

Most elders prefer to remain living in their own homes for as long as possible (Clough et al., 2004; Gitlin, 2003). Research indicates that home can have profound personal and symbolic meaning in old age (Sixsmith & Sixsmith, 2008; Tinker, 1997). For example, home can represent security and comfort, and remaining at home can enable elders to maintain a level of control over their lives as they age (Sixsmith & Sixsmith, 2008). However, remaining at home may not guarantee that elders will have a positive experience of care nor maintain the level of control they desire. In past research, elders living in residential care reported greater autonomy over their own decisions than elders receiving domiciliary care (Boyle, 2004). For example, some decisions (e.g., when to bathe) depended on when carers were present. The quality of domiciliary care available to elders is, therefore, likely to influence whether remaining at home is preferable.

1.6.2. Challenges Impacting the Domiciliary Care Sector

Across health and social care services, staff recruitment and retention remain significant challenges (Health and Social Care Committee, 2022). In July 2022, there were approximately 165,000 vacancies in adult social care services in England, a 52% increase in the number of vacant posts in a single year (Skills for Care, 2022). The health and social care system has been described as “gridlocked” (Care Quality Commission [CQC], 2022, p. 4), leading to “a tsunami of unmet need” (p. 7) and negatively impacting people’s experiences of care.

The domiciliary care sector faces substantial financial challenges, including increasing demand, limited public funding and rising costs to care providers (Age UK, 2019). Staffing challenges, market changes and the impact on care quality are explored below.

1.6.2.1. Staffing and recruitment

The domiciliary care sector has the highest staff turnover rate in adult social care (Jefferson et al., 2018). In a recent workforce report, 88% of domiciliary care providers reported difficulties recruiting staff (CQC, 2022). Low pay and limited pay progression have been identified as significant issues, with retail and hospitality wages often exceeding the wages carers receive (Health and Social Care Committee, 2022). Recruitment and retention are also believed to be impacted by the poor public perceptions of care work (Hall et al., 2017).

Staffing shortages mean that, despite rising demand, care providers cannot take on additional care packages and large numbers of people remain in hospital awaiting care (CQC, 2022). The high turnover rate also has significant implications for elders' experiences of domiciliary care, as continuity of carers is highly valued by elders (Healthwatch England, 2017). Elders may receive short and rushed visits if providers have insufficient staff. Improving carers' working conditions could encourage staff retention and be an important step towards improving quality of care (Equality and Human Rights Commission [EHRC], 2011).

1.6.2.2. Changes to the domiciliary care market

In addition to workforce challenges, the quality of care providers can deliver is understood to be limited by continued underfunding and the "fragmented, unstable and diverse" domiciliary care market (Glendinning, 2012, p. 294). For example, care provision spans the public, private and voluntary sectors, and new services open and close down frequently because of financial challenges (United Kingdom Homecare Association [UKHCA], 2021).

Elders are faced with navigating a complex system. As domiciliary care is means-tested, some elders are eligible for local authority-funded care and others fund their own care (self-funders) or use a combination of these two means (Bennett et al., 2018). Publicly funded domiciliary care services in England are mostly delivered by private and voluntary sector providers (UKHCA, 2021).

Care can be purchased by individuals or local authorities (Glendinning, 2012). Elders who are eligible for local authority-funded care in England can choose to receive the money they are entitled to as a direct payment or personal budget (Bennett et al., 2018). Direct payments allow individuals to choose how to spend the money they receive. Personal budgets allow individuals to decide how to use or receive the money and who it is managed by (Glendinning, 2012). Both options were promoted as part of the reforms proposed by the 2010 to 2015 Coalition Government (Department of Health and Social Care, 2012). Direct payments and personal budgets were developed to provide a more personalised approach to care, increasing individual choice and control (Bennett et al., 2018), yet have been criticised for creating a more complex market and diverse workforce (Glendinning, 2012). For example, elders can opt to employ personal assistants (PAs). However, there are no formal requirements for PAs to have minimum qualifications, possibly placing elders at risk (Glendinning, 2012).

Thomas and Hollinrake (2014) argue that UK social care reforms have created autonomy and choice only for those with the most financial resources. They state that reforms have taken a neoliberal form, utilising market competition to cut service delivery costs. Time-and-task commissioning, in which care providers are paid an hourly rate, remains the dominant approach to domiciliary care in England (Jefferson et al., 2018). Care providers are required to provide their services in a way which cuts costs and can reduce quality of care, such as by offering shorter care visits (England, 2010). Gethin-Jones (2012) argues that the time-and-task model has created a separation between “doing care and being caring” (p. 11), with the emotional component of care deprioritised.

Some commissioners are adopting outcomes-based commissioning, in which providers are given a budget per individual. Care can be arranged flexibly to work towards specific outcomes (Jefferson et al., 2018), such as engaging in social activities. This approach remains in development and numerous barriers have been identified. For example, some domiciliary care providers lack the capacity needed to address elders’ desired outcomes (Glendinning et al., 2008).

1.6.2.3. Quality of care

Staffing shortages and growing demand, alongside market instability and cost-saving actions by commissioners, are understood to significantly impact the quality of care elders receive (Hall et al., 2017; Health and Social Care Committee, 2022). Quality of care is not uniform and considerable variation in ratings exists across domiciliary care providers (Jefferson et al., 2018). In CQC inspections[1], providers serving smaller numbers of people generally receive higher ratings (CQC, 2017).

Good quality care has been associated with reliability, flexibility in relation to the care plan, continuity of carer, and the qualities and attitudes of carers (Francis & Netten, 2004). Elders have reported that domiciliary care can provide valuable social interaction and a desirable alternative to residential care (Sykes & Groom, 2011). However, research also suggests that domiciliary care can lack flexibility, with short care visits limiting opportunities for social interaction and for caring relationships to form (Thomas & Hollinrake, 2014). Elders have reported dissatisfaction with the timing of their care visits, care which lacks dignity and respect, and a lack of continuity of carers (Sykes & Groom, 2011).

1.6.3. Theoretical Context

This section examines three theories of care and caring. Each theory is summarised, critically reviewed and its relevance to domiciliary care for elders is considered. Theories focusing on psychological or integrative elements of care were selected, in accordance with the research focus on elders' personal and psychological experiences of care.

1.6.3.1. Theory of human caring (Watson, 1979)

The theory of human caring has been highly influential in the field of nursing (Cara, 2003), though is applicable to all human-to-human caring interactions. The theory was originally proposed in 1979 and there have been many subsequent revisions and expansions (e.g., Watson, 1985, 1988, 1996, 1997, 2002, 2009; Watson & Foster, 2003). Watson's theory promotes an authentic human relationship between caregiver and recipient (Watson, 2009). Caring is not considered a commodity which can be bought and sold, but a way of being (Watson, 2009). The theory therefore focuses on the approach to caring, rather than the physical delivery of care.

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[1] CQC is the independent regulator of health and social care services in England. Inspections assess whether services are safe, effective, caring, responsive, and well-led (CQC, n.d.).

The original theory proposed ten 'carative' factors, presented in Table I, which honour the human dimension of caring and the importance of the subjective experience of those being cared for (Watson, 1997). The 'caritas processes' describe how each factor can be demonstrated in practice, such as by displaying loving kindness and being authentically present during care interactions (Watson, 2001).

Table I

Ten 'Carative' Factors (Watson, 1979)

'Carative' Factor	Description
1) Formation of a humanistic-altruistic value system	Respecting and treating each person as an individual and receiving satisfaction through giving
2) Instillation of faith-hope	Incorporating faith and hope into care to support well-being and acceptance of health status
3) Cultivation of sensitivity to one's self and others	Identifying and accepting individuals' needs and values, including one's own
4) Development of a helping-trusting human care relationship	Using effective communication skills to demonstrate warmth and empathy and build rapport
5) Promotion and acceptance of expression of positive and negative feelings	Allowing the sharing of positive and negative feedback to and from the caregiver and recipient
6) Systematic use of scientific problem-solving in decision making	Encouraging shared problem-solving by explaining, guiding, and providing feedback as part of care
7) Promotion of interpersonal teaching and learning	Recognising that both caregivers and recipients are continuously teaching and learning from each other

8) Provision for supportive, protective, or corrective mental, physical, sociocultural, and spiritual environment	Manipulating the environment to support mental and physical well-being (e.g., providing comfort and privacy)
9) Assistance with gratification of human needs	Supporting fulfilment of needs, from physical (e.g., food, ventilation) to emotional
10) Allowance for existential, phenomenological and spiritual forces	Accepting and allowing spiritual beliefs, including those different from one's own

A key component of the theory is the transpersonal caring relationship (Watson, 2001), which relies on spiritual and personal connection between the caregiver and recipient. The caring relationship goes beyond the person's objective care needs to attend to the integrity and dignity of the whole person (Watson, 1999). Another key component is the caring occasion or moment, which is when the caregiver and care recipient meet in such a way that caring occurs (Watson, 1988b, 2001).

Interventions based on Watson's theory have been associated with improved emotional well-being and confidence for care recipients, and increased job satisfaction among nurses (Wei et al., 2019). The theory has been praised for conceptualising caring for both the caregiver and recipient, such as how caring can contribute to caregivers' own self-actualisation (Cara, 2003). Self-actualisation is considered to involve accepting one's inner self and realising and achieving one's full potential (Maslow, 1962).

Although Watson's theory is not specific to elders or social care, there are examples of how it can be applied to working with elders and their caregivers (e.g., Bernick, 2004; Sentürk & Küçükgüçlü, 2021). For example, the theory promotes attending to elders' spiritual needs and preserving dignity (Wadensten & Carlsson, 2003). The presence or absence of the 'carative' factors may inform explanations of elders' experiences of domiciliary care. For example, poor quality care has been associated with dehumanisation, such as elders feeling treated like a number, rather than a person (CQC, 2013). In support of the theory, existing research has identified the importance of the relationship between elders and domiciliary carers (S. Hughes & Burch, 2020; Sykes & Groom, 2011).

The theory has been criticised as intangible, with the 'carative' factors emphasising the psychosocial aspects of care and largely omitting the physiological aspects (Barker et al., 1995; Barker & Reynolds, 1994). It is undeniable that appropriate attention to physical needs is also essential to high quality domiciliary care. Watson's theory outlines the approach to caring, rather than how to specifically attend to medical conditions, for example. Other critics have recognised how carers' work can be limited by how they themselves are cared for and valued by their employers (Kurtz & Wang, 1991), indicating the need to consider factors beyond the one-to-one caring relationship. Domiciliary carers face considerable pressures because of the demands on services and have reported feeling stressed and lacking support (Ravalier et al., 2019). These stresses may limit their ability to provide the care Watson's theory promotes.

1.6.3.2. The Roy adaptation model (Roy, 1970)

The Roy adaptation model (RAM) was first published in 1970, aiming to explain and define nursing practice (Roy, 1970). The model suggests that humans adapt to the environmental stimuli they experience (Roy & Andrews, 1999). Stimuli can include behaviours, beliefs and experiences. Health is not understood as the absence of disease, but the ability to cope with life experiences, including illness and unhappiness (Roy & Andrews, 1999). In application to care, the theory would suggest that the carer's role is to facilitate positive adaptation to the environmental circumstances individuals face.

RAM integrates physiological and psychological aspects of coping by suggesting two subsystems of adaptation: the regulator subsystem (physiological coping, such as internal bodily processes) and the cognator subsystem (psychological coping) (Roy, 2009). There are four modes of adaptation defined in the model

(Roy, 2009). The modes present areas in which problems can occur and adaptation can be promoted.

The four modes are:

1) Physiologic mode
   This mode encompasses the physical and chemical processes required to meet basic physiological needs (e.g., nutrition). Domiciliary carers can assist by supporting with food preparation and hygiene, for example.
2) Self-concept mode
   The self-concept encompasses how individuals view themselves, including personal identity and body image. Personal identity includes moral and spiritual aspects of the self. Domiciliary carers may promote coping by respecting individual identities and preferences.
3) Role function mode
   This mode focuses on the roles individuals can hold within society, including primary (e.g., male, female), secondary (e.g., mother, carer) and tertiary roles (e.g., chairperson of group). Roles are believed to promote social integrity. Carers may support individuals to fulfil their roles or cope with changes to them.
4) Interdependence mode
   Interdependence refers to the meaningful relationships and support systems individuals have. Adaptation includes receiving sufficient love and respect from others. Domiciliary carers can support this mode by forming relationships with individuals characterised by trust and communication.

RAM is not specific to elders or domiciliary care, as it was originally developed as a model of nursing. However, the model has been applied to the care of elders to both evaluate and enhance care experiences. For example, care plans based on RAM have been associated with improved quality of life for elders living in nursing homes (Maslakpak et al., 2015). ‘Role function mode’ has been used to understand the difficulties elders experience transitioning into caregiver roles for their spouses (Shyu, 2000) and, therefore, may also be applied to understanding elders’ experiences of adapting to a cared-for role.

The model has been critiqued for complexity and ambiguity (Shosha & Taher Al Kalaldeh, 2012), such as the overlapping nature of the self-concept, role function and interdependence modes (Mastal & Hammond, 1980). Although RAM identifies areas for care to focus on and can guide practice, the model itself provides little practical information on how to support adaptation. However, RAM has been widely used to develop care plans, training and interventions, which link the theory to practice and have been associated with improved quality of life for those being cared for (Ghanbari-Afra et al., 2023).

1.6.3.3. Caring life-course theory (Kitson et al., 2022)

The caring life-course theory (CLCT) provides an explanation of a person's care needs across the lifespan, from the person's own perspective and the perspectives of care providers. The theory was developed in response to discipline-specific theories of care, which the authors claim cannot capture the dynamic and complex interplay of factors influencing care delivery and care experiences over one's life-course.

CLCT employs the fundamentals of care framework (Kitson et al., 2013) to present how universal care needs, including psychological, relational and physical needs, can be met in terms of care provision. Universal or fundamental care needs are the needs everyone requires to be met to stay alive, have optimal health and well-being, and a peaceful death (Kitson et al., 2022). The framework incorporates the role of the relationship between the carer and care recipient, the integration of multiple care needs, and the context in which care takes place (e.g., home or hospital). Context also includes health, social, cultural, structural and temporal factors influencing care needs and provision (Kitson et al., 2022). The theory explains how care needs, self-care capabilities, and the readiness to accept care from others develop from life experiences. For example, self-care capability may reduce with financial hardship, changes in health, or after receiving excessive care from others.

The theory is interdisciplinary, recognising that caring transcends disciplines (Kitson et al., 2022), and is therefore applicable to domiciliary care. The lifespan perspective explains how care needs can increase with age and following changes in context (e.g., bereavement of spouse). CLCT also offers an explanation for why readiness to accept domiciliary care may differ across individuals and over time. For example, elders may struggle to recognise their care needs because of cognitive or psychological factors, such as dementia or depression. The theory would suggest that elders' experiences of domiciliary care are impacted by their ability to care for themselves and accept care from others, and whether care provision meets their specific needs.

CLCT was informed by existing theory, such as Erikson's model of psychosocial development, which proposes stages of human development from infancy to old age (Erikson & Erikson, 1998). However, as CLCT is newly developed, there is currently a lack of empirical research directly examining it. The authors acknowledge that "refinement, testing and operationalisation" are required to enhance practical utility (Kitson et al., 2022, p. e17). CLCT does provide practical suggestions for care provision, which could be applied to domiciliary care. For example, the authors propose creating a care biography, which is an account of the person's care history, capabilities and expectations.

1.6.3.4. Comparison and summary of relevant theory

The theory of human caring and RAM were developed for application to nursing, whereas CLCT is an interdisciplinary theory of caring. CLCT may therefore be considered more directly applicable to domiciliary care. Additionally, CLCT may display greater sensitivity to context, as it recognises the role of socio-economic factors on care needs and care provision (Kitson et al., 2022). All three theories are relevant to understanding care experiences. RAM and the theory of human caring may better explain how caring is best enacted, whereas CLCT focuses on explaining changing care needs and provision across the lifespan.

None of the three theories focus specifically on elders, which could be advantageous for understanding how one's past influences one's care experiences. However, theories of ageing may enhance understanding of how elders experience domiciliary care compared to younger people. For example, the theory of Gerotranscendence suggests that, with advancing age, one's perspective of the world shifts from largely rational and materialistic to spiritual (Tornstam, 1989). Gerotranscendence theory therefore recognises ageing as a spiritual experience, which may impact elders' perceptions and experiences of care.

There are similarities in how the theories highlight the importance of the carer's role and the relationships formed. Although they have integrative elements, the three theories privilege the relational and psychological aspects of care, above the physiological and practical. This perceived separation represents Cartesian dualism, a term used to refer to a dichotomous understanding of the mind and body. Cartesian dualism was named from the writing of the 17th century philosopher René Descartes depicting the mind and body as independent entities (Matthews, 2017). However, reduced reference to the mind or body may represent the significant differences between the two, rather than suggesting a separation or prioritisation of one above the other (Paley, 2002). The theories may therefore focus upon the more subjective social and psychological aspects of care, without negating the importance of the physical and practical aspects.

1.6.4. Research into Domiciliary Care

Research into domiciliary care predominantly falls into the four categories identified below.

1.6.4.1. Performance monitoring

A significant body of research into domiciliary care focuses on assessing the performance of services, often in relation to commissioning and cost-saving. For example, some studies evaluate particular reforms (Thomas & Hollinrake, 2014), commissioning approaches (Gethin-Jones, 2012; Glendinning et al., 2008), funding arrangements (Baxter et al., 2021; Moran et al., 2013) or performance in relation to quality indices (Jones et al., 2007). Some studies include direct feedback from elders (e.g., Francis & Netten, 2004; Moran et al., 2013; Netten et al., 2007; Thomas & Hollinrake, 2014), however, the focus is often constrained to providing feedback on services or responding to particular quality indices. Owing to the aims or methodology, this research may not offer the opportunity for elders to provide more detailed accounts of their care experiences.

1.6.4.2. The experiences of carers and care providers

Within the existing academic literature, a body of research focuses on the experiences of carers and the challenges facing carers and care providers. Domiciliary carers have shared experiencing fatigue and stress because short visits limit their ability to deliver high-quality care (Atkinson & Crozier, 2020). Carers have also reported difficulties separating their professional responsibilities from their personal and moral values (Jarling et al., 2020). For example, carers have reported spending longer than their allotted time with clients to provide further care. Despite the challenges, domiciliary carers can perceive caring as meaningful and joyful (Jarling et al., 2020). Although these studies provide valuable insight into care provision, it is important that academics, commissioners and health and social care professionals seek the voices of elders receiving care, to learn from their direct experiences.

1.6.4.3. Health conditions and dementia

Some studies into domiciliary care have focused on elders with particular health conditions (e.g., Carot-Sans et al., 2022; Huang et al., 2021) and there is a body of research focused on the experiences of elders diagnosed with dementia and their family caregivers (e.g., Hoel et al., 2021; Olsen et al., 2021). Elders living with dementia have reported that it is important for domiciliary carers to recognise them as individuals and respect their abilities, despite their diagnosis (Olsen et al., 2021). Owing to the nature of this research, the focus is often upon how impairments and characteristics of particular conditions interact with care needs, rather than upon the experience of receiving domiciliary care more broadly. For example, Huang et al. (2021) investigated how domiciliary carers assisted individuals with spinal cord injuries to undertake specific ADLs, such as washing their feet.

1.6.4.4. International research

There are significant differences in how care is funded, commissioned and provided across the world (see 1.5.1.1.), including within Europe (Bihan & Martin, 2006; Genet et al., 2012). Cultural differences also impact how elders are valued, such as elders being highly respected in Chinese culture (Lovell, 2006). Because of these differences, applying international research into domiciliary care to the UK context requires careful interpretation. International research can provide useful knowledge of how domiciliary care can support elders and be of value to them. For example, international research has highlighted the importance of the caring relationship (Porat & Iecovich, 2010) and continuity of care (Rostgaard, 2011). However, elders' experiences of domiciliary care may differ according to the care system available to them. For example, UK elders have reported dissatisfaction with the inflexible care associated with the UK's time-and-task commissioning model (Gethin-Jones, 2012). In France, care for elders in their own homes is generally provided by nurses and there is a mandatory insurance scheme in place to subsidise care costs (Robertson et al., 2014). With care provided by nurses, there may be differences in the relationships formed and care activities undertaken compared to care provided by carers without nursing training in the UK.

1.7. Literature Review

1.7.1. Literature Review Strategy

A scoping review of the literature was undertaken to examine the key concepts related to elders' experiences of receiving domiciliary care, the main sources of evidence available, and the gaps in the literature (Arksey & O'Malley, 2005).

Booth et al. (2016) proposed a framework which was employed to establish the parameters of this review. The following aspects were considered:

- Who? – Elders receiving domiciliary care in the UK
- What? – Personal experiences of receiving domiciliary care

- How? – Describe accounts of the personal experiences of elders receiving domiciliary care

Based on these factors, the scoping review question was formulated as follows: “What is known from the existing literature about how elderly individuals describe their experiences with domiciliary care?”. The current research understands *experiences* as subjective perceptions of reality. Experiences may refer to events themselves and/or interpretations of them (Daher et al., 2017).

Five databases were searched to identify relevant literature: PsycINFO, Social Care Online, Academic Search Complete, CINAHL Complete, and Science Direct. Searches were undertaken in June and July 2022. Relevant grey literature and additional studies were identified using Google Scholar and reference lists.

The search terms employed were: (“elders” OR “elderly” OR “old people” OR “older people” OR “old age” OR “later life” OR “aged”) AND (“homecare” OR “domiciliary care” OR “care at home”) AND (“experiences” OR “perspectives” OR “attitudes” OR “views”). The results of the database searches were filtered to include only studies written in English. The results were hand searched for relevance and the exclusion criteria were applied (see Appendix A). A substantial volume of the research identified focused on medical/health care provided at home (e.g., ‘hospital-at-home’ services or nursing care), informal care, took place outside the UK, or did not include the views of elders themselves.

Inclusion in the final review was limited to studies published within the last 15 years. This parameter was to maximise the socio-cultural relevance of the search returns, in acknowledgment of the social, political and legislative changes which have occurred during this time frame. These changes include the *Care Act 2014* and the social care reforms introduced by the 2010-2015 Coalition Government. The process of searching the literature and reviewing the search returns is presented in the flowchart in Figure 2.

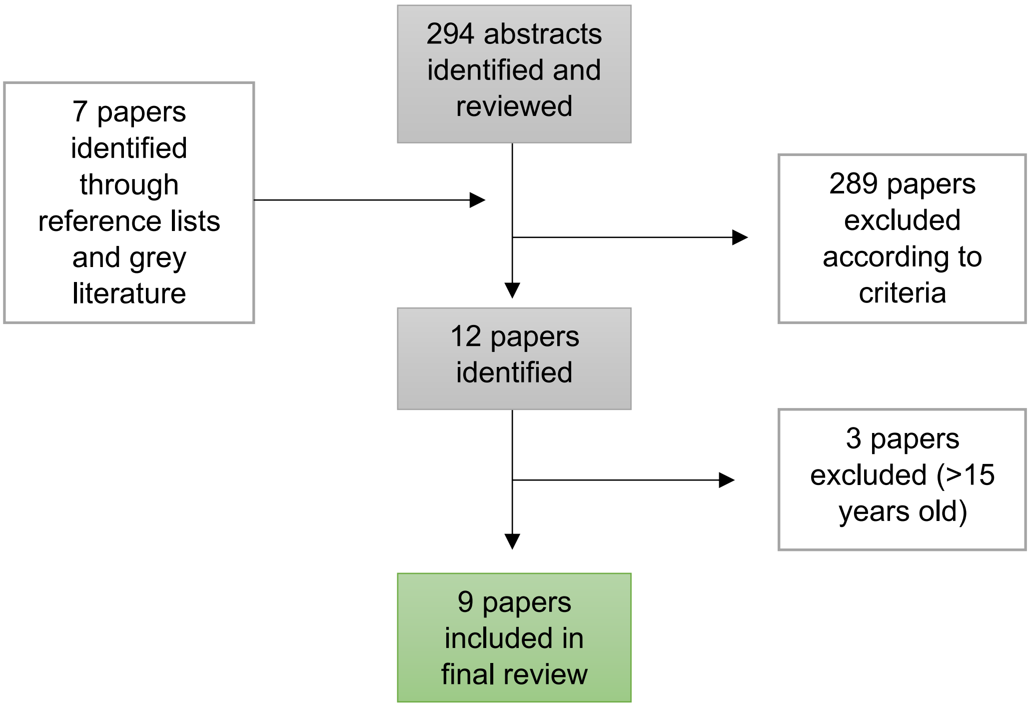

Figure 2

Literature Search Returns

1.7.2. Scoping Review Results

Nine papers were identified which included elders' accounts of their experiences of receiving domiciliary care within the UK. These papers are summarised and critiqued below.

1.7.2.1. Quality of domiciliary care

Five papers were identified which reported elders' perspectives on the quality of the domiciliary care they receive.

The first paper is a report by the CQC (2013), which summarises feedback from elders obtained as part of 250 inspections of domiciliary care providers. Inspections took place between April and November 2012. Feedback was gained from visiting elders' homes, telephone interviews, questionnaires and webforms. The report outlines what services were doing well and what needed to improve, but does not consistently and clearly delineate which information was reported by elders themselves. The report states that many elders valued care which was delivered with compassion and respect, and carers who were kind, gentle and friendly. Elders shared positive experiences of carers who supported their independence and choice, and care plans which were individualised. Late or missed visits reportedly led to elders feeling vulnerable and undervalued.

The report provides useful knowledge of which aspects of domiciliary care are valued by elders and an overview of the experiences reported by a large sample. Direct quotations from elders are provided, yet the report lacks the depth needed to understand elders' rich, individual experiences of domiciliary care, such as what care personally means to them. The findings suggest that domiciliary care can impact elders' psychological well-being, such as late visits leading to feelings of vulnerability. However, the report does not provide the detail needed to understand the impact on quality of life, long-term well-being, or identity, for example.

The second paper identified was a quality report by Healthwatch England (2017), which presents feedback from surveys, listening events and service visits. Healthwatch is an independent statutory body, whose role is to gather and promote service users' views (Healthwatch England, 2017). The report, "Home Care: What people told Healthwatch about their experiences", includes feedback from 3415 domiciliary care service users, their families and staff members, and covers 119 domiciliary care providers and 52 Healthwatch organisations across England. The report does not focus specifically on the experiences of elders themselves. Direct quotations from elders are provided, however, similar to the CQC report, some information is given without clear acknowledgment of its source. The main findings were the identification of four themes considered essential to high quality domiciliary care: care planning, skills and qualifications, choice and consistency, and communication and feedback. The report states that service users sometimes found that carers lacked time to offer the care they needed and that forming relationships with carers was important because of the personal nature of the care required. Continuity of care (e.g., seeing the same carer regularly) was considered important for building trust and rapport.

The findings of this report point to the importance of the care relationship and elements such as trust, continuity and control over one's care. However, there is a lack of in-depth exploration of the impact of these factors or what these experiences mean to elders. The report does not provide demographics, making it difficult to understand which elders' views have been represented and who may have been excluded.

As the third, fourth and fifth identified papers all utilise surveys to collect service-user feedback, they will be individually described and then critiqued collectively. The third paper presents the results of a postal survey of domiciliary care service users in Northern Ireland (Department of Health, Social Services and Public Safety [DHSSPS], 2010). Descriptive statistics are reported from 4321 eligible responses. Findings included that 92% of respondents reported that they always trusted their carers, and 89% reported being treated with respect and dignity. 28% reported that care visits were too short to meet their needs.

The fourth paper is a survey of domiciliary care service users in Wales, commissioned by the Older People's Commissioner for Wales (Llewellyn et al., 2013). The survey explored six elements of domiciliary care: being listened to; having knowledgeable, trained and skilled carers; having sufficient time for care; continuity of care; quality of care; and signposting. Responses were received from 1029 elders and analysed using content analysis. Nearly 85% were "satisfied" or "very satisfied" with their care in relation to these elements (Llewellyn et al., 2013, p. 167).

The fifth paper outlines a mixed methods study undertaken in Northern Ireland (Patient and Client Council [PCC], 2012). The study used 700 surveys, interviews with 38 people, and discussion groups with 170 people, to collect feedback from elders receiving domiciliary care and their relatives. Descriptive statistics were reported and 87% rated the services they received positively. Concerns relating to quality of care included short or poorly timed visits, inflexibility of the service, lack of continuity of carers, and poor staff training.

The last three studies described rely primarily upon survey data, with the exception of the study by the PCC (2012) which also incorporates interviews and discussion groups. For the organisations initiating these studies, surveys provide useful summary data about the opinions of large numbers of people. However, the data lacks the detail necessary to understand the reasons for the responses given, information which could inform changes to care provision. For example, in the DHSSPS survey, the extent to which respondents reported their care supported their independence varied, yet no explanation is provided for this (DHSSPS, 2010). Therefore, these studies provide limited insight into elders' personal experiences of receiving domiciliary care, such as the psychological impact or meaning of their experiences. There are also differences between the care systems in Northern Ireland, England and Wales (UKHCA, 2021), which may limit the direct applicability of this research to elsewhere within the UK.

1.7.2.2. Human rights and domiciliary care

Two reports were identified which explored the experiences of elders as part of a formal inquiry into the human rights of older people receiving domiciliary care in England (EHRC, 2011; Sykes & Groom, 2011). The interviews detailed in the first report (Sykes & Groom, 2011) contributed to the full inquiry documented in the second report (EHRC, 2011). The inquiry was deemed necessary because of the high level of potential risk to human rights associated with care delivered in the home environment, which is more difficult to regulate than care delivered in institutional settings (EHRC, 2011).

The first report presents the findings of interviews with 40 elders receiving domiciliary care across four local authority areas (Sykes & Groom, 2011). The interviews identified areas of good practice in which domiciliary care protected and promoted the human rights of elders, and areas of concern where there were risks to human rights.

Areas of good practice included elders having continuity of carers, which was an important factor in reducing loneliness. Elders often praised carers' skills and professionalism and there was an example of a carer identifying that an elder was being financially abused by supposed friends. The detail provided by the interviews enabled specific valued aspects of care to be identified. For example, positive experiences of care were associated with the trusting relationships elders formed with their carers. Elders described valuing conversation, laughter and friendship with carers, and receiving psychological support.

Risks to elders' human rights included receiving disrespectful treatment, such as dignity being compromised during personal care. This treatment was experienced as stressful and depressing. Domiciliary care was described as "essentially intrusive" (p. 57) by nature of taking place within people's homes, with care routines potentially interfering with the right to respect for one's private life.

It was noted that some of the more challenging experiences of care appeared to occur at the outset: when care was first needed. Elders feared loss of autonomy and control and needed time to adjust to having care, particularly if it was needed following a crisis. Domiciliary care was described as something elders appreciated, but did "not necessarily welcome" (p. 14), and many elders reported feeling that care had been foisted upon them.

The second report, "Close to home" (EHRC, 2011), summarises evidence gained from 1254 individuals, including service users, service providers and public authority figures. Therefore, the report does not solely focus on the experiences of elders themselves. Data was gathered using interviews, focus groups, surveys and written evidence submissions.

The inquiry identified that domiciliary care could have a positive impact on people's lives. Elders shared that seemingly small things made a significant difference to their well-being, such as being supported to maintain their appearance. Some elders valued conversation more highly than support with practical tasks. This research demonstrates that *how* care is delivered is important to elders, such as the attitude of carers and whether elders are treated as individuals.

Breaches of human rights included elders failing to receive adequate food and drink, being left in soiled clothing, being ignored or disrespected, and being unable to participate in valued activities. These breaches affected both physical and mental health. For example, elders reported feeling stripped of self-worth. Only approximately half of the elders, friends and family members reported being satisfied with the care received, suggesting a worrying level of dissatisfaction.

These two reports provide rich accounts of elders' experiences of domiciliary care, from a human rights perspective. The EHRC report states that there is a need to capture elders' voices more effectively and critiques the use of paper-based surveys with elders because of potentially excluding those with visual or cognitive impairments. These elders may be at greater risk of care which breaches their human rights. The inquiry has been labelled "highly critical", because of the instances of poor care described (Glendinning, 2012, p. 297), which demonstrates the importance of gaining a deeper understanding of elders' experiences, beyond satisfaction ratings. Use of individual interviews within elders' home environments allowed detailed information to be gathered, enabling specific areas of good practice and concern to be highlighted.

1.7.2.3. Qualitative research into elders' experiences of domiciliary care

Very few studies within the academic literature explored the in-depth, personal and psychological experiences of elders receiving domiciliary care in the UK. The literature search identified two examples of qualitative research focused on elders' experiences of domiciliary care, which were not part of assessments for quality standards or human rights inquiries (S. Hughes & Burch, 2020; Palmer et al., 2015).

The first study, by Palmer et al. (2015), utilised semi-structured interviews with 26 people aged 55-102 receiving domiciliary care in the London borough of Bexley. Interviews took place in participants' homes and were analysed using content analysis. They found that participants were generally satisfied with their care, yet most also highlighted issues. The concept of satisfaction provides limited understanding of elders' experiences. As the authors themselves note, reports of satisfaction may represent gratitude for care or anxiety about giving negative feedback. Participants shared positive experiences of interactions with regular carers and reported that care could boost their self-esteem. Participants criticised inflexible care and the poor reliability, frequency and duration of care visits. These issues led to unmet social, emotional and rehabilitation needs.

Similar to Sykes and Groom (2011), this research highlights the significance of the transition into care. The transition period was described as disruptive and anxiety-provoking, with the need to adapt to change impacting participants' well-being. Participants reported difficulties negotiating new boundaries within their home and some felt that their home's aesthetic qualities were altered by it becoming a working environment for carers. Palmer et al. (2015) reported that receiving domiciliary care for the first time appeared to change the relationship between participants and their homes, which was challenging for participants.

Following their recognition that satisfaction surveys are insufficient to understand experiences of care, the authors' use of individual interviews effectively elicited in-depth accounts of elders' experiences of domiciliary care. However, in some interviews, family members spoke on behalf of elders and therefore the elder's unique personal experiences may not have been captured. No rationale is given for this, yet it is an important factor to be addressed in future research as elders' and relatives' experiences may differ. Additionally, the use of content analysis may have prioritised the reporting of frequently-occurring experiences, meaning nuanced findings or areas of disagreement may not be presented (Vaismoradi et al., 2013). As this research took place within a single London borough, some of the experiences shared may relate specifically to services within that borough. Care needs, provision and experiences may also differ in more rural communities (Milne et al., 2007). However, the themes and impacts described generally speak to receiving domiciliary care as a broad experience and make little reference to local specifics.

The second study aimed to understand elders' experiences of domiciliary care and whether care impacts on elders' sense of self (S. Hughes & Burch, 2020). Seventeen participants receiving domiciliary care in the East of England were recruited. There were three phases of data collection: 1) Narrative-biographical interview, exploring participants' care experiences and identity, 2) Diary completion, with participants noting thoughts and reflections on their care over two weeks, 3) Follow-up interview, exploring the diary entries. Not all participants completed each stage. Narrative inquiry was used to identify themes across the three datasets. The study found that a supportive relationship with carers, developed through continuity, could promote feelings of autonomy. Care could be delivered in a way which supported the participant's sense of identity, such as recognising their individual likes and dislikes. Ageing and the need for care impacted participants' sense of self.

The study highlights the importance of considering domiciliary care in relation to elders' "identity, individuality and well-being, as much as cost-effectiveness or quality" (p. 910). The findings suggest that domiciliary care can impact on sense of self and refer to the transition into receiving care as an important period for elders. Participation in this study required the ability to communicate in writing for the diary exercise, which would have excluded some elders with physical or cognitive difficulties. Most participants were recruited from day centres, suggesting that this study is unlikely to have captured the views of elders who cannot leave the home. These are examples of how researchers' decisions can impact knowledge production. Housebound individuals may have a different relationship with, and reliance upon, domiciliary care, which may affect their sense of self and well-being.

1.7.3. Conclusion

The literature reviewed provides useful insight into the experiences of elders receiving domiciliary care in the UK. For example, the research demonstrates the potential for domiciliary care to impact elders' psychological well-being, both positively and negatively. Multiple studies emphasised the importance of the relationship formed between elders and their carers and how personalised care, which promoted autonomy, was highly valued by elders. Several studies reported findings which suggested the transition into receiving domiciliary care was significant for elders. This transition was associated with changes in independence, control, and the relationship with one’s home. The literature also suggested that receiving domiciliary care can impact elders’ sense of self.

The results of the scoping review promote the use of qualitative methodology to investigate elders’ experiences of domiciliary care. Survey methods, and research utilising satisfaction measures, failed to access the richness and depth of elders’ experiences and thus provided limited understanding. Surveys are also inaccessible for some elders.

The scoping review highlights the paucity of literature into elders’ experiences of domiciliary care in the UK. When gathered, the views of elders are primarily presented in reports monitoring quality of care, gained via service-user feedback methods. Qualitative research, specifically focused upon the personal experiences of elders receiving domiciliary care, from the perspectives of elders themselves, is extremely limited. Only one study published in the last five years was identified (S. Hughes & Burch, 2020). There were no identified studies published since the Covid-19 pandemic.

Despite several studies suggesting that the transition into receiving domiciliary care is significant for elders, no studies directly explored this. A further literature search identified no UK literature specifically focused on the experiences of elders receiving domiciliary care for the first time.

1.8. Current Research

1.8.1. Study Rationale

For many elders, domiciliary care is their first experience of receiving formal care. Requiring care for the first time can occur suddenly following illness, injury or bereavement of a family carer and may be considered a significant change to daily life. Multiple psychological theories identify the significance of transitions and life events (e.g., Carter & McGoldrick, 1989; Erikson, 1963) and suggest that how elders first experience receiving domiciliary care could significantly impact their well-being.

The existing research suggests that receiving domiciliary care can impact elders' sense of self and that the transition period, when one first begins receiving domiciliary care, presents challenges for elders' emotional well-being (S. Hughes & Burch, 2020; Palmer et al., 2015; Sykes & Groom, 2011). There is some existing research exploring elders' first experiences of residential care (O'Neill et al., 2020, 2022; Thein et al., 2011), yet there are currently no UK studies specifically exploring elders' experiences of receiving domiciliary care for the first time. As more UK elders receive domiciliary care than residential care (NAO, 2021; ONS, 2022a), this represents a significant gap in the literature.

Further research is required to understand elders' experiences of first receiving domiciliary care. Little is currently known about what it means to elders to receive domiciliary care for the first time or how this impacts their view of themselves or psychological well-being.

1.8.2. Research Questions

This study aims to explore elders' accounts of receiving domiciliary care for the first time. The research questions are:

1) How do elders describe their experiences of receiving domiciliary care for the first time?
2) How do elders view themselves since receiving domiciliary care for the first time?

1.8.3. Clinical Relevance

The knowledge gained from this study will provide a greater understanding of elders' experiences of first receiving domiciliary care. Gaining insight into experiences by exploring themes is a useful and necessary first step, given the lack of existing research. The findings could form the basis for further research on practical recommendations to improve elders' care experiences.

The themes generated in this study may inform training for domiciliary care providers or healthcare professionals aimed at supporting elders during the transition process. The findings may assist clinical psychologists working directly with elders, providing consultation to organisations, or contributing to policy, to better understand the experiences of this marginalised group at a significant time in their lives.

2. METHODOLOGY

2.1. Chapter Overview

This chapter begins with a description of the ontological and epistemological positions underpinning this research. The research design, procedure and ethical considerations are then presented. The chapter concludes with an outline of the analytic approach.

2.2. Philosophical Assumptions

Ontology and epistemology are branches of philosophy which underpin all stages of research (Moon & Blackman, 2014). Ontology refers to theories about the nature of existence and reality, whereas epistemology refers to theories about the nature of knowledge and how knowledge is produced (Braun & Clarke, 2021c). In other words, ontology refers to what is real and epistemology refers to what can be known (Braun & Clarke, 2021c).

This research adopts a critical realist approach and recognises that ontology and epistemology cannot be neatly separated (Barad, 2007). Critical realism was originally described by Bhaskar (1978) and is believed to lie in between the paradigms of realism and relativism. Realism suggests that there are phenomena which exist independently of human knowledge of them (Sayer, 2004). In contrast, relativism suggests that reality is dependent upon human interpretation and knowledge (Braun & Clarke, 2013). Critical realism suggests that there is an objective reality which exists, yet the knowledge we can access as researchers is subjective and socially influenced (Madill et al., 2000).

In line with critical realism, the research questions can be considered ontologically realist as they explore phenomena which are believed to exist, such as experiences. Yet, the research can be considered epistemologically relativist, with language and culture believed to lead to different interpretations and perspectives on experiences. Within a critical realist approach, research provides access to subjective realities which are situated in context and interpreted, rather than objective truths (Braun & Clarke, 2021c). The researcher is considered to be part of the context they are exploring and the knowledge produced in the research is informed by both the participants' and researcher's perspectives (Willig, 2016). In this research, the participants' and my own historical and cultural contexts provide a lens through which participants' experiences of receiving domiciliary care for the first time are examined.

2.3. Design

A qualitative approach using semi-structured interviews was selected following consideration of the research aim, questions and epistemological stance. Qualitative research aims to understand or explore meaning, and how meaning is made (Braun & Clarke, 2013) and was therefore compatible with the aim of exploring elders' accounts of receiving domiciliary care for the first time, and the research questions focusing on both experiences and meaning.

Qualitative research can allow participants to describe their experiences in their own words, which can give voice to disadvantaged or often-excluded groups (Pistrang & Barker, 2012). Elders are underrepresented in academic research generally (Thake & Lowry, 2017), particularly those with greater care needs (Backhouse et al., 2016). This research acknowledges that elders are the people best placed to describe their own experiences and needs (Haak et al., 2021).

Given the lack of literature focusing on elders' experiences of receiving domiciliary care for the first time, individual interviews were chosen to enable in-depth exploration of the topic and produce detailed accounts of the experiences and perspectives of elders themselves (McGrath et al., 2019). Interviews were semi-structured to allow for further exploration of pertinent experiences, nuances and contradictions (Pistrang & Barker, 2012), recognising the likely variation in elders' care experiences.

2.4. Setting

Interviews took place in participants' own homes. All participants were living in Essex, Southeast England, and were receiving domiciliary care from the same provider.

Eight domiciliary care providers based in Essex were invited to support recruitment to the study and one provider agreed. The provider is a privately-owned and independent local company, with a Care Quality Commission (CQC) rating of 'outstanding'. Their services include personal care, rehabilitation, home help and companionship. The company provides domiciliary care to elders living in the local area with varying care needs, including clients living with dementia or Parkinson's disease and those requiring post-stroke or end-of-life care.

The domiciliary care provider was interested in the research topic and enthusiastic in their offer of support. Meetings and telephone conversations took place between the care provider and I to discuss recruitment, risk assessment, the inclusion and exclusion criteria, and to share and discuss study materials.

2.5. Participants

2.5.1. Recruitment

Opportunity sampling was used, with care provider staff asked to identify potential participants from amongst their clients, have an initial conversation with the client about the research, and ask whether they consented to be contacted by me. A poster was produced to advertise the study (Appendix B) and care provider staff were provided with information to aid selection of appropriate participants (Appendix C).

2.5.2. Inclusion and Exclusion Criteria

The inclusion criteria were:

- Over age 65
- Receiving (or previously received) domiciliary care

- Capacity to consent to taking part in a research study
- Sufficient level of verbal communication in English to partake in conversation without an interpreter

The exclusion criteria were:

- Cognitive or communication difficulties which would restrict participation in an interview

The above criteria were informed by literature focusing on increasing the inclusion of elders in research, which advises against rigid exclusion criteria (Thake & Lowry, 2017), such as those based on the presence of cognitive, communication or sensory difficulties alone (Backhouse et al., 2016; Bowling et al., 2019). These difficulties are common reasons for requiring domiciliary care (NHS Digital, 2022). Adaptations can be made to support the participation of elders (Bowling et al., 2019). For example, this study offered large print materials.

It is advised that exclusion criteria are minimised to those which would hinder participation (Bowling et al., 2019; Thake & Lowry, 2017), therefore no upper age limit was imposed. No restrictions were placed relating to the participant's duration of care, reason for needing care, or living situation, to maximise participation and increase the relevance of the findings to a greater number of elders.

2.5.3. Number of Participants

Reflexive thematic analysis (TA) was the selected analytic approach. An overview of TA will be provided in section 2.9. There are no agreed-upon criteria for determining the number of participants required for TA (Braun & Clarke, 2022). Data saturation is a criterion for discontinuing data collection on the basis that no further new insights can be gathered (Saunders et al., 2018). However, the concept of data saturation was not applicable as reflexive TA assumes that knowledge is generated and new insights remain possible (Braun & Clarke, 2021d, 2022; Malterud et al., 2016).

Qualitative researchers have been advised to evaluate the appropriate sample size throughout the research process and make a context-dependent decision (Braun & Clarke, 2022; Malterud et al., 2016; Sim et al., 2018). I aimed for a sample size sufficient to demonstrate patterns in meaning and experience across participants, whilst maintaining the ability to explore the experiences of individuals (Braun & Clarke, 2013). My supervisory team and I agreed on recruiting 6-12 participants, informed by the TA literature (Braun & Clarke, 2013) and the concept of information power (Malterud et al., 2016). The concept of information power suggests that the more information the participants hold in relation to the study's specific aims, the fewer participants are needed (Malterud et al., 2016).

Ten participants were recruited over a five-month period. One further participant initially expressed a willingness to participate but declined during the pre-interview discussion on the day of their interview.

2.6. Service User Consultation

The involvement of service users, stakeholders and representatives from the population under study in the research process can increase the "real-world connection" of the research and provide unique and practical expertise (Tierney et al., 2016, p. 510). For the research to be meaningful and relevant to the lives of elders receiving domiciliary care, it was important to consult with people with personal knowledge and experience of domiciliary care.

Two consultation activities were undertaken: 1) A consultation with a representative from the University Programme's service user and carer group, which advises on research, and 2) A consultation with elders who had previously received domiciliary care. These consultations took place at different stages in the research process and, therefore, the perspectives and advice offered related to various areas of the research design, procedure and materials. A summary of the suggestions which arose is provided below.

The University's service user and carer group comprises of individuals with lived experience of emotional difficulties and mental health service use and carers of individuals with these experiences. I met with a service user from the group for a discussion about the research proposal during the early planning stages. The service user was supportive of the research and provided suggestions related to recruitment, participants, study materials and providing feedback to the services involved. For example, they advised interviewing both men and women, as they believed there might be differences in how receiving care is perceived. I therefore aimed to recruit both male and female participants.

A meeting with elders with experience in receiving domiciliary care, consisting of two people, took place following the formation of the proposed interview schedule. The elders shared their support for the research topic. They provided suggestions relating to the interview schedule, proposed participant group, and interview approach/technique. For example, the prompt "What was it like for you to accept help from someone else?" was added. They reported that the interview questions and prompts related to areas which, from their experiences, felt important to explore, such as potential concerns about having another person in the home environment.

2.7. Procedure

2.7.1. Pilot Interview

I conducted a pilot interview involving two elders who had experienced receiving domiciliary care. The pilot interview aimed to test, and gain feedback on, the proposed interview schedule, trial the practical aspects of the interview (e.g., timings, use of the audio-recorder), and allow me to gain familiarity with the interview procedure. I hoped to ensure that the interview questions felt clear and appropriate to elders with experience in domiciliary care. Pilot interviews can also support researchers to practise interview techniques and identify flaws in the interview design (Majid et al., 2017), and anticipate challenges which may arise whilst interviewing (Malmqvist et al., 2019).

The pilot interviewees reported that the interview provided the opportunity for them to speak about significant aspects of their experience, such as adapting to changes in roles, and think about the meaning of their experience of first receiving domiciliary care in a way they had not done so before. They made suggestions relating to the interview questions and prompts. Informed by their feedback, my research supervisor and I agreed upon some changes to the interview schedule, such as some additional prompts and alterations to question wording. For example, the prompt "Has having care changed any of your relationships in any way?" was added, and three questions eliciting contextual information (e.g., "How often do your carers visit?") were added at the beginning of the interview to gently open the conversation. The pilot interview also allowed me to consider how best to phrase sensitive questions, such as a question referring to changes in identity.

2.7.2. Interviews

I interviewed all participants face-to-face in their own homes, with none opting to be interviewed remotely. A risk assessment was undertaken (Appendix D) and Covid-19 and lone working safety precautions were followed.

Each interview began with me introducing myself and the study. Time was allowed for informal conversation, for the purpose of building rapport (Jacob & Furgerson, 2012). Length of this discussion varied greatly across participants, with some keen to know more about my background and studies. I presented the participant information sheet (PIS; Appendix E) and gave participants time to consider the information and ask questions. I then provided the consent form (Appendix F) for participants to read, consider and sign. Basic demographic information (Appendix G) was collected once consent was given, to provide context to the interviews and to ease participants into the interview questions (Jacob & Furgerson, 2012).

The interview schedule (Appendix H) was used as a flexible tool, with prompts employed when necessary to further explain a question or to encourage participants to expand on their experiences. I utilised follow-up questions to specifically address and respond to the unique experiences shared.

Interviews were audio-recorded. The duration of the audio recordings ranged from 44 to 83 minutes. Approximately one hour was the expected duration shared during recruitment. Participants were verbally debriefed and provided with a debrief sheet (Appendix I). Consent was revisited and all participants confirmed their consent. Participants were invited to select a pseudonym. Seven participants chose to select their own pseudonyms, with three participants opting for me to choose. I thanked the participants for their time and provided the opportunity for them to ask any further questions.

2.7.3. Transcription

I manually transcribed the interviews to begin gaining familiarity with the data. An orthographic transcription style was adopted, with spoken words recorded verbatim, as recommended in preparation for TA (Braun & Clarke, 2013). Punctuation was added to enhance readability. Names were replaced with pseudonyms, and potentially identifiable information was removed or altered and placed within [ ]. Transcription conventions (Appendix J) were informed by Braun and Clarke (2013). Completed transcripts were compared against the original audio recordings and reviewed for anonymity.

For TA, it is advised that data is transcribed “to an appropriate level of detail” (Braun & Clarke, 2021c, p. 269). Where I considered significant sections of the recording (>1-minute duration) to be irrelevant to the research aim (such as a participant’s phone call interrupting the interview), these were omitted from the transcript. Omissions were acknowledged within [ ].

2.8. Ethical Considerations

2.8.1. Ethical Approval

The study was registered with the University of East London (UEL). Ethical approval was sought and granted from UEL School of Psychology Ethics

Committee, prior to beginning data collection (Appendices K-M). The research has been guided by the British Psychological Society's (BPS) Code of Human Research Ethics (2021).

2.8.2. Informed Consent

The BPS guidelines state that potential participants should be given sufficient information about the research to allow them to make an informed decision as to whether to take part (BPS, 2021). Potential participants were provided with the PIS (Appendix E). An information video was also created, which could be shown to potential participants who might find it difficult to read or understand a large quantity of written information. The PIS and video provided information about the study, what participation would involve, data protection, confidentiality, the benefits and potential disadvantages of participation, and the right to withdraw. The PIS included information about how data would be used and stored and details of how the research findings may be disseminated on completion. Contact details for myself, the research supervisor and the Chair of the School of Psychology Research Ethics Committee were provided.

Potential participants and their relatives were offered the opportunity to speak or meet with me to gain more information about the study or ask any questions, prior to participation.

The intended procedure was for the care provider staff to give potential participants the PIS, or show them the information video, during an initial recruitment discussion about the research. Upon meeting with potential participants on their scheduled interview dates, the potential participants mostly reported that they had been verbally given information about the research, yet had not been given the PIS or seen the information video. Therefore, I provided all potential participants with a copy of the PIS on the interview date and talked through the information thoroughly with each person at this time.

The PIS was provided to participants to read and consider prior to asking them to sign the consent form. I gave participants the opportunity to ask questions and seek clarification. The consent form (Appendix F) required participants to indicate that they had read and understood the PIS. Participants were required to sign the form to demonstrate that they agreed to take part in the study.

Before each interview, I reminded participants of the right to withdraw and their ability to withdraw their data from the study for up to three weeks after participation.

2.8.3. Confidentiality and Anonymity

Confidentiality, and the limits to confidentiality, were outlined on the PIS and revisited verbally prior to each interview. Care provider staff were aware of the person's participation. However, it was explained that information disclosed in the interview would only be identified to the care provider if the safety of the participant, or others, was at risk and following discussion with the participant and research supervisor.

Participants were informed verbally, and via the PIS, that the information they provided would be anonymised. In acknowledgment that names can have psychological meaning to individuals (Allen & Wiles, 2016), participants were invited to choose their own pseudonym. Pseudonyms were used in all written material, except for the consent form, to refer to the participants' accounts.

Data was stored in accordance with a comprehensive data management plan (Appendix N) and participants were informed about how data would be used and stored via the PIS. Participants' names and contact details were communicated to me via UEL email or telephone and were stored on a password-protected database, securely and separately from consent forms, audio recordings and transcriptions. Interviews were audio-recorded using a password-protected audio recording device, which was transported securely in a locked case, along with the signed consent form. Hard-copy consent forms were scanned and then shredded, and electronic versions were stored separately from other research data. Potentially identifiable information, such as the names of people or places, were replaced or removed during transcription. Audio recordings were deleted following transcription.

Participants gave consent for anonymised quotes from their interviews to be used in the write-up and other dissemination activities. They were informed that any data shared with examiners or the supervisory research team would be anonymised. As explained in the PIS, anonymised data will be stored securely by the supervisory research team for a maximum of three years following the study's completion. After that time, all research data will be deleted.

2.8.4. Debriefing

At the end of each interview, participants were provided with the debrief sheet and given the opportunity to reflect on their experience of taking part. This included discussing any emotional responses or learning arising from the interview. I reminded participants of their right to withdraw and asked if they would like to receive a summary of the research findings.

The debrief sheet (Appendix I) contained information about sources of support, data protection, dissemination of the research findings, and the contact details of myself, the research supervisor and the Chair of the School of Psychology Research Ethics Committee.

2.8.4.1. Potential distress

The PIS informed participants that the information they shared in the interview was up to them, but that they may wish to discuss things they have found difficult about needing care. Participants were informed that they could have a break or stop the interview at any point, if they were finding the conversation upsetting. During each interview, I monitored for verbal and nonverbal signs of distress and provided time at the end of the interview to discuss any emotional responses. The PIS and debrief sheet both contained contact details for organisations which may be able to provide support to participants if they had experienced any distress related to participation.

My research supervisor and I agreed upon actions to minimise risk to both me and the participants, as outlined in the risk assessment (Appendix D).

2.9. Analytic Approach

2.9.1. Thematic Analysis

Thematic Analysis (TA) was considered to be the most appropriate analytic approach to address the research questions. TA is a method of data analysis which develops, analyses and interprets patterns across a qualitative dataset, called themes (Braun & Clarke, 2021c).

Other analytic approaches were considered, such as Narrative Analysis (NA) and Interpretative Phenomenological Analysis (IPA). These were ruled out because the research questions focus on identifying patterns of meaning across individuals, which NA is not appropriate for, and which is not the primary focus of IPA. NA is used to understand how participants assign meaning to their own experiences using the stories they tell and focuses on the storied accounts of individual participants (Moen, 2006). IPA studies the personal meaning of the inner lived experience of individual participants and does not focus on identifying broad themes across participants' experiences (Braun & Clarke, 2013; Pistrang & Barker, 2012). Therefore, both NA and IPA provide a more idiographic focus, rather than focusing on investigating meaning across the dataset, which the research questions demand.

TA identifies patterns of meaning in experiences across individuals (Braun & Clarke, 2013) and was therefore the most appropriate fit for the research questions. I hoped that, by identifying patterns of meaning in how elders describe their experiences of receiving domiciliary care for the first time, the practical utility of the results would be enhanced and provide useful learning for care providers and health professionals to apply.

An advantage of TA is the theoretical and methodological flexibility offered (Braun & Clarke, 2013). TA can be used both inductively and deductively (Braun &

Clarke, 2021b). In this analysis, codes and themes were developed from the data (inductive) and yet the construction of themes was also influenced by my own experiences, context, perspectives, and knowledge of existing theory (deductive), such as the theories outlined in Chapter 1.

TA can be considered a family of methods, with multiple forms of TA used (Braun & Clarke, 2021a, 2021b). Reflexive TA was the specific analytic approach employed. Reflexive TA acknowledges and embraces the subjectivity of the researcher (Braun & Clarke, 2021b). In reflexive TA, analysis is considered to be an interpretative and reflexive process, in which themes are generated by the researcher, informed by their values, experience, assumptions and skills (Braun & Clarke, 2021a). Coding is organic, with no coding framework required (Braun & Clarke, 2021b). Reflexive TA can be used from a critical realist approach to identify contextualised, interpreted realities (Braun & Clarke, 2021c) and was therefore compatible with the research's epistemological stance.

2.9.2. Stages of Analysis

Analysis was guided by the six phases of reflexive TA described by Braun and Clarke (2021c). My employment of these phases is outlined in Table II.

Table II

Six Phases of Reflexive TA

Phase	Description
1) Familiarisation with the dataset	I became immersed within the data by conducting the interviews, manually transcribing, and thoroughly reading and re-reading the transcripts. I noted initial thoughts relating to each interview and the collective dataset.
2) Coding	The full dataset was coded systematically using NVivo (1.7) software for Windows. Coding was at both the semantic and latent level, with code labels aiming to provide useful analytic

	descriptions of the data. Data was coded for multiple patterns of meaning, resulting in some data extracts with multiple codes. Analysis was both theory- and data-driven. Appendix O provides a list of initial codes. Appendix P provides example coded transcripts.
3) Generating initial themes	Handwritten notes and mind maps were used to identify shared patterns of meaning across the dataset. Codes which appeared to share core ideas were grouped together to form themes, which aimed to capture broader, shared meanings (see Appendix Q for examples). This was as an active and interpretative process, with the themes constructed by the choices and interpretations I made (Braun & Clarke, 2021c). Themes were generated with the research questions in mind, but an openness for nuance and unanticipated findings was maintained.
4) Developing and reviewing themes	I returned to the original coded data extracts, and then the full dataset, to assess whether the themes were meaningful and reflective of the data. I considered whether the themes represented the most important patterns of meaning across the dataset, in relation to the research questions, and whether data had been overlooked. I examined the relationships between themes and revised and collapsed themes accordingly. Appendix R presents examples of provisional thematic maps.
5) Refining, defining and naming themes	I reviewed each theme to consider what core concept was being communicated. Names were given accordingly, aiming to be both concise

	and informative. A synopsis of each theme was written, focusing on the story told by each.
6) Writing the research report	In reflexive TA, writing is considered part of the analytic process (Braun & Clarke, 2021c). Refinement of themes continued during writing. Data extracts are used in Chapter 3 to provide a coherent story of the dataset, addressing the research questions and going beyond a simple description of the data.

2.9.3. Quality Control

Quality control was considered in the production of this research. The literature advises that the different analytic approaches used in qualitative research are evaluated in relation to their own epistemological and ontological positions (Braun & Clarke, 2021b; Yardley, 2008). Scientific concepts often used in assessing the rigour of research, such as reliability, bias and objectivity, are incoherent with reflexive TA, because knowledge and meaning are considered to be contextual and researcher subjectivity is embraced as a tool for producing knowledge (Braun & Clarke, 2021b). Other forms of TA, such as coding reliability TA (Braun & Clarke, 2021b), employ different quality measures (e.g., inter-rater reliability), as they are based upon different assumptions.

Braun and Clarke (2021b, 2023) have provided guidance for undertaking high quality reflexive TA. For example, researchers are encouraged to clearly outline their analytic procedure (Table II), explain and justify use of their chosen form of TA (section 2.9.1.), and avoid making common assumptions, such as that TA is one homogenous approach. This guidance was considered alongside the four dimensions for evaluating the quality of qualitative research described by Yardley (2000, 2008, 2017): sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. For example, the analysis demonstrates *sensitivity* to the specific data, rather than imposing pre-conceived themes.

Another key consideration for quality control in reflexive TA is the practice of reflexivity. For example, researchers are encouraged to state and acknowledge their own perspectives and social standpoints (Braun & Clarke, 2021b).

2.9.4. Reflexivity

Researcher reflexivity is the practice of critically reflecting on one's own role as a researcher (Braun & Clarke, 2021c), to recognise and acknowledge one's position within the research and the impact of this on the research process and outcome (Berger, 2015; Horsburgh, 2003). Reflexive research understands that knowledge is situated, and shaped by the researcher's practice and decision-making (Braun & Clarke, 2021c).

Journaling is one method for engaging with reflexivity (Braun & Clarke, 2021c). A reflexive journal was kept throughout the research process (see Appendix S for extracts). In addition, qualitative researchers are encouraged to "own" their perspectives (Elliott et al., 1999, p. 221) and reflect on the assumptions and choices made throughout the research (Braun & Clarke, 2021c; Finlay & Gough, 2003). In addition to the personal context presented in Chapter 1, I present the following reflections which I have held in mind, related to my experiences and position.

I have interest in elders' first experiences of domiciliary care from both a personal and professional perspective. I encountered and gained knowledge of domiciliary care from my experience of my Nan first receiving domiciliary care and from my roles in stroke and respiratory healthcare services, where many elders I worked with required domiciliary care. These experiences have shaped my beliefs that caring is an admirable and yet undervalued profession, with services restricted by the economic and political climate. Whilst I am not an insider researcher, my personal observations of domiciliary care are likely to have influenced the research process, such as my interpretation of participants' responses and the rapport built with participants.

Because of the age difference between myself and the participants, I was aware of the differences in the cultural and socio-political contexts we had experienced. I strived not to make assumptions about the participants' experiences, although I am aware that this is not possible in its entirety. My clinical psychology doctoral training at the University of East London has further highlighted to me the importance of social and cultural context in understanding emotional experience.

As a White British, cisgender female, of working-to-middle class background, I recognise that intersectional aspects of identity, different to my own, may impact upon how elders describe their experiences of receiving domiciliary care for the first time. For example, from my position, I may overlook differences in the experiences of elders from racialised or other disadvantaged communities. These reflections influenced my decision to include an interview question relating to aspects of identity.

3. ANALYSIS

3.1. Chapter Overview

This chapter reports and explores the themes generated in the reflexive thematic analysis. Demographic information is presented to contextualise the data. A thematic map provides a visual representation of the themes. The themes are then explored individually, with data extracts used to evidence my interpretations.

3.2. Participant Demographics

Ten participants were interviewed. Self-reported demographic information is presented in Table III. Five participants identified as male and five identified as female. Participants were aged between 76 and 95 years (*M* = 85.5 years). All participants described themselves as White and either British (*n* = 5) or English (*n* = 5). All but one of the participants lived alone. To understand participants' individual care needs and contexts, participants were asked to self-report their reasons for needing domiciliary care, the frequency of their care visits and their duration of care.

Table III

Participant Demographics and Care Information

Pseudonym	Age	Gender	Ethnicity	Living Situation	Reason for Receiving Domiciliary Care	Frequency of Care Visits	Duration of Domiciliary Care
Finley	91-95	Male	White British	Lives alone	Administering medication, Companionship	Twice daily	1 year
Doreen	86-90	Female	White English	Lives alone	Washing and dressing, Personal care, Food preparation	Once daily	3 years
Neil	91-95	Male	White English	Lives alone	Washing and dressing, Personal care, Administering medication,	Twice daily	1 year

					Food preparation		
Peter	76-80	Male	White British	Lives alone	Emotional support, Companionship	Once daily (weekdays only)	1 year
Mr Zebedi	76-80	Male	White English	Lives alone	Administering medication, Personal care	Once daily	3 years
Yvonne	81-85	Female	White British	Lives alone	Washing and dressing, Food preparation	Twice daily	10 years
Mrs Bordeaux	91-95	Female	White English	Lives alone	Washing and dressing, Personal care, Food preparation, Mobility	Four times daily	5 years
Louise	81-85	Female	White British	Lives with spouse	Food preparation	Once daily	1 year
Mary	81-85	Female	White British	Lives alone	Washing and dressing, Mobility, Food preparation, Emotional support	Twice daily	11 years
Oliver	86-90	Male	White English	Lives alone	Food preparation, Companionship	Once weekly	1 year

Note. Pseudonym format varies according to participant choice. Age ranges are provided for anonymity.

Participants' reasons for requiring domiciliary care included support with washing and dressing, medication, food preparation, mobility (e.g., getting in and out of bed), personal care (e.g., personal hygiene, catheter care), companionship and emotional support. Some participants had a single purpose for their care (e.g., food preparation), whereas others had multiple care needs and required support with a range of activities during each visit. The frequency of care visits varied across participants, according to their needs and preferences. The length of time participants had been receiving domiciliary care for ranged from one year to eleven years (M = 3.7 years).

3.3. Overview of Themes

Two overarching themes were constructed, each comprising of two themes. The first overarching theme, 'A new, important relationship', contained the themes: 1) Carers are like friends, and 2) Support to continue with life. The second overarching theme, 'Who am I now? Changing view of oneself', contained the themes: 1) Struggling to accept the need for help, and 2) Lost parts of the self. The final thematic map is displayed in Figure 3.

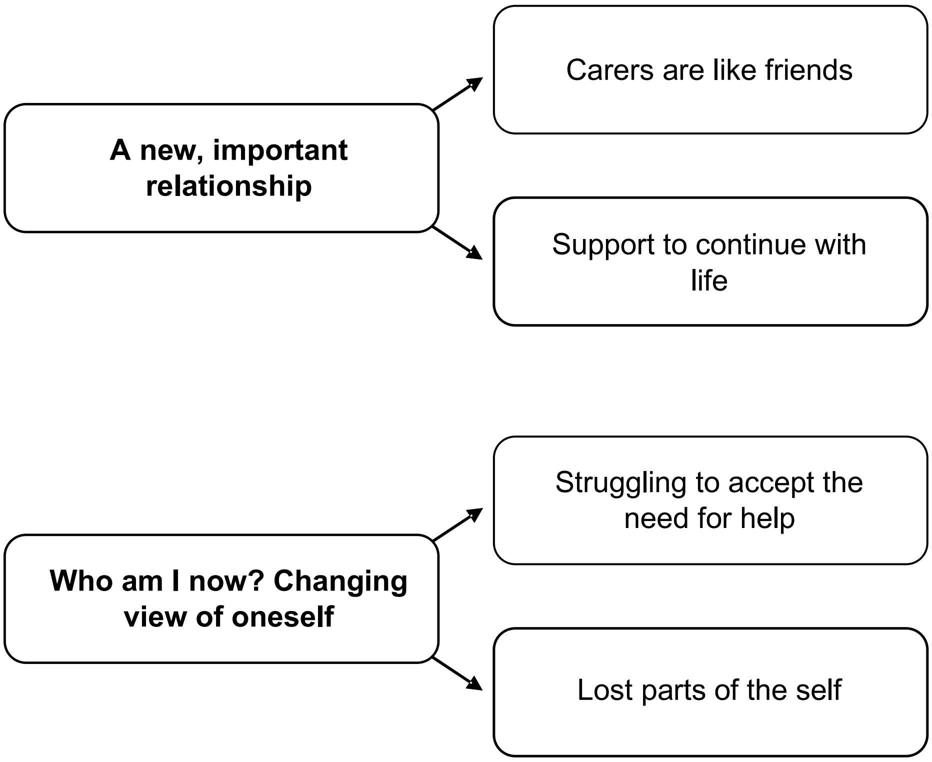

Figure 3

Final Thematic Map

In the data extracts below, minor changes have been made to enhance ease of reading, such as the removal of repeated words (e.g., “I, I, I”). Omissions are identified by ellipses.

3.4. A New, Important Relationship

The overarching theme ‘A new, important relationship’ was developed to represent the way in which participants described the relationship they formed with their carers as fundamental to their experience of receiving domiciliary care for the first time. Participants described how this relationship developed through the reciprocal process of getting to know the carer and the carer getting to know them, negotiating roles, and forming a partnership. The relationship participants formed with their carers was described as highly valued and crucial to enabling them to accept care into their lives. This first overarching theme encompasses two themes: ‘Carers are like friends’ and ‘Support to continue with life’.

3.4.1. Carers Are Like Friends

This theme explores the core pattern of meaning, expressed throughout the interviews, that the relationship formed between elders and their domiciliary carers is experienced by elders as similar to a friendship. Multiple participants explicitly referred to their carers as “*friends*” or “*like friends*”, suggesting that they characterised the relationship in this way.

> *“it’s like having friends popping in. It really is.”* (Yvonne)
>
> *“I really do love them. They’re like friends to me.”* (Mary)
>
> *“And it’s friends calling, not carers. Yeah, they're friends.”* (Peter)

Through establishing a relationship akin to friendship, within professional boundaries, participants described trusting, valuing, and relying upon their carers. It appeared that trust was built through a process of carers getting to know the participants individually and adapting their care in response.

> *“they get to know how you like things done, you see? Because we're all, you might know, individuals ((laughs)).”* (Doreen)

For example, Oliver shared appreciating that, as his regular carer knows what he likes and needs, he does not have to ask for things. In contrast, Mary shared valuing that her carers ask her before they do things as, to her, this shows respect for her home and for her as a person. The differences in their accounts appear to demonstrate their carers’ efforts to honour their personal preferences.

> *“I don't have to tell her what to do. She comes in. “Right. You want your porridge. You want your tablets.” And she always makes sure that I have two cups of tea before I go.”* (Oliver)

> *"They will always ask you if they could do something. They never waltz into your home as though it's theirs. They respect the fact it's your home and if they want to do something or look for something, they would always ask."* (Mary)

Participants described how the relationship-building process went beyond their carers getting to know their individual routine and needs, to getting to know them as a person: "*they get inside you to know what makes you tick*" (Doreen). Participants related this to being treated as a "*human being*" (Mary), as individual personalities and identities were respected and valued. This close relationship created comfort and appeared to open the opportunity for participants to receive emotional support and be open about their needs, which enhanced well-being and feelings of self-worth.

> *"I know I can be myself with the carers. And relax with them. And they're never going to criticise me or condemn me or in any way. Because that's not in their nature"*
>
> *"they make me really feel as though I'm important and that is a huge thing. It really is."* (Mary)

Mary's description of feeling "*as though I'm important*" may relate to the devaluing of elders in a neoliberal society (Peacock et al., 2014). It appears that she may doubt her importance and be critical of herself and her worth. Mary's description indicates that relationships with carers characterised by a sense of friendship can enable elders to continue feeling valued, despite changes in their abilities and the need to start receiving domiciliary care.

Some participants understood the development of a close relationship between themselves and their carers as inevitable because of the nature of the work carers do, such as providing personal care.

> *"But when you see to the intimate jobs they do, that nobody else would, even your own family wouldn't do for you, you can't help having that bond present. It's just it's impossible not to."* (Mary)

Having this close relationship was presented as desirable and, at times, essential to enabling elders to accept this level of care. In conjunction, participants demonstrated an awareness of the need for carers to maintain professionalism and carers were described as able to meet this balance. Peter referred to his carers as "*professional friends*". However, there were examples of participants appearing to transgress professional boundaries in their way of understanding their carers. For example, Mary reported, "*I really do love them*", and Peter stated, "*God I really look upon them as friends and family*." Yet, participants recognised that maintaining professional boundaries was important for both themselves and their carers "*because it's their job after all*" (Mary).

> *"And you've got to have those laws, especially in care work, because if you start getting too friendly with people, it would mess up the relationship for the care that they have to give you"* (Mary)

Mary appears to be acknowledging the professional responsibilities carers have, such as the need to safeguard those they are caring for. She may be recognising that, although she values a close relationship with her carers, professional boundaries are in place for their mutual safety. Carers are professionals, not friends, and yet the participants characterised the relationship as a friendship, experienced it in this way, and portrayed this very positively.

The language of friendship, love and family may be the vocabulary available to elders to explain the depth of feeling they have for their carers. Participants described how their carers had become part of their lives, and how they felt they were part of their carers' lives. Mary remarked, "*how privileged I am to let them be, let me be part of their lives*". This closeness occurred through a process of getting to know each other's daily activities and interests. For example, Yvonne reported enjoying hearing about her carer's wedding and seeing photos of her wedding dress. The sharing of everyday details about one another's lives was frequently described by participants as an important and enjoyable aspect of their care.

> *"we build up a lovely relationship. You know, you get to know the girls and their families and things like that. They bring their photographs in to show me, which I so enjoy. It's like having a friend in twice a day."* (Yvonne)
>
> "*they've all been very open, yes. And I live my life through their families, to some extent…Whether their children they've got their exams, …whether they…played football, and did they win?"* (Doreen)

The sharing of family photographs appears symbolic of a friendship to Yvonne and suggests mutual, personal interest in one another's lives. For Yvonne, this may demonstrate that her carer views her as a person with likes and interests and a history, rather than solely a client they support.

Doreen's statement demonstrates the significance of the caring relationship to her life and suggests that her current level of activity is not enough to feel that she is living. This sense of living depends on being part of the lives of others. It is possible that hearing about, and feeling part of, their carers' lives lessen feelings of sadness elders experience in relation to the limitations of their own lives.

Participants acknowledged that, with advancing age, friendships are lost because of death, illness or physical distance: "*If you live too long, your friends disappear*" (Doreen). Therefore, relationships with carers enable elders to maintain a level of social connection. This may have been particularly relevant as nine participants lived alone.

Louise spoke about how her conversations with her carers provide "*a window on the world*", suggesting a sense of isolation and separation from the rest of society, which interactions with carers help to reduce.

> *“Well, it's nice for us to see other people. It's a window on the world, isn't it? Outside. But we get out. Less. (.) Where people are willing to talk about where they've been and what they're doing. That's been interesting.”*
>
> *“It's good to remind people. Remind* yourself *that ((pause)) the active, that the world outside your house is an active place. And that there are people, who happened to pop in every day or every other day, have lives that reflect the pace of so much of our society. That society is moving, and moving on… People are still working. They're still having leisure time. And you get a sense of balance. Really, that it would be easy to become bittered, I think. You know, that all this was out of your grasp anymore.”* (Louise)

This account suggests that, with age and loss of abilities, elders can feel excluded and marginalised, as though living separately from the rest of society. Louise portrays a sense of hopelessness and sadness about her own situation. Her account suggests that her relationships with her carers lessen these feelings, by allowing her to connect with “*the world outside*”. This demonstrates an important contribution of the caring relationship, beyond the immediate care needs, which participants considered to be a valued part of their first experiences of receiving domiciliary care.

A sense of friendship was presented as a significant factor in enabling receiving domiciliary care for the first time to be an acceptable and enjoyable experience. Some participants reported that this relationship was the most valuable aspect of their care.

> *“There's not much I don't know about them. And I think that is half the secret, because you're just treating people as friends.”* (Mary)
>
> *“I look forward to them coming. And we have a laugh. And it's lovely.”* (Peter)

Mary and Peter appear to be perceiving their relationships with their carers as uncomplicated and mutual. A friendship constitutes a knowable relationship type.

By categorising the relationship in this way, care may appear less threatening to elders and more acceptable, with elders positioning themselves as peers to their carers, rather than dependent upon them.

3.4.2. Support To Continue With Life

This theme explores the core pattern of meaning, expressed throughout the interviews, that domiciliary carers support the elders they care for to “carry on” with life. Some participants described being physically dependent upon care for survival, yet many described their relationships with their carers as providing them with hope for the future, motivation, and the emotional support needed to carry on living in the best way they can, rather than giving up.

Some participants expressed feeling dependent upon care to stay alive. When asked about the impact of care on her life, Mrs Bordeaux reported that care had “*made it possible*” and shared, “*Otherwise I couldn't survive. I do realise that.*” Mrs Bordeaux implied that she would die without her care, as she is dependent on care for “*Everything. Feeding. Washing*”.

Participants’ accounts suggested a sense of vulnerability and dependence, demonstrating the significance of the role of domiciliary carers in their lives. Participants were positioned as holding this fear, leading to an appreciation of how reliable their carers were, “*Even if they’re late, they always come*” (Mrs Bordeaux), and expressions of anxiety when waiting for carers to arrive, “*calm down and count up to however many*” (Doreen).

Finley reported that the “*thing that really is* [important]*, is that they're coming*”. Participants’ accounts suggested a level of desperation, as though they were reassuring themselves that their carers would arrive. The possibility of the carers not coming is portrayed as an intolerable option. Some elders may face grave outcomes, including physical harm, prolonged isolation, or situations where their dignity is compromised, such as being unable to access basic facilities like toilets. In extreme cases, the consequences could even result in death.

The way participants described their relationship with their carers as something which supports them to continue with life suggested that living meant more to them than just physical survival.

> "*Now I'm of the opinion that it's not going to cure anything, it's just going to make life liveable, which is what it's all about."*
>
> "*I think that, the care is something that I realise I need. My life needs it. I shall continue*." (Mr Zebedi)

This could suggest that having domiciliary care supports Mr Zebedi's life to operate in a way which is acceptable to him personally. It implies a resistance, an unwillingness to tolerate a life of lower standards than he feels he is deserving of. "*I shall continue*" is ambiguous and could represent the decision to continue with both care and life.

Care is positioned not just as support to "carry on" with life, but as an alternative to giving up on life. Participants' accounts suggest that, although life is changing, receiving domiciliary care can support elders to continue living a life which is meaningful to them and prevent them from giving up.

> *"It gives me confidence to carry on, really. I think, I'm not the sort of person who gives up, but I don't know at this time in my life, I might just give up and not bother anymore. I can't imagine that I would. But you don't know, do you? And er. So that means everything to me"* (Mary)

In discussing receiving domiciliary care for the first time, some participants expressed an awareness, or a questioning, of the possibility of giving up, similar to Mary. Domiciliary care was positioned as support which enabled them to continue to value themselves and their lives. In contrast to societal narratives depicting needing help as a weakness, Mary's account suggests that accessing domiciliary care demonstrates strength and self-respect. To Mary, her decision to accept care shows that she is unwilling to give up with life because of her age and mobility difficulties. This decision allows her to continue to be "*not the sort of* *person who gives up*". Accepting care is presented as extremely important for Mary's well-being and sense of self: "*that means everything to me*."

The participants did not describe what giving up would look like. It is positioned as a frightening and unknown alternative. One may speculate that giving up could represent death or emotional breakdown, yet the participants appeared unable or avoidant of voicing this or considering this themselves.

> *"But again, you know you've got you to* [have care]*. You either accept it or, well, I don't know what the alternative is if you don't accept it."* (Yvonne)

Another expression of this theme was the frequent descriptions of carers as uplifting and motivating. Participants shared feeling able to do activities which they would feel anxious to attempt without the emotional support and confidence their carers provide, such as having a bath or leaving the house. Multiple participants reported that their carers leave them feeling good or feeling ready for their day.

> *"they leave me on an up and I'm thinking, "Right, off your backside, get dressed, get out there, get over to the [sports] club. Walk down. You can do it. You've got your stick. You've got your alarms.""* (Peter)

Participants acknowledged the possibility of physical and emotional decline and the risks of reduced activity in older age. Care was positioned as important in reducing the likelihood of this decline occurring.

> *"Because you can <u>so</u> easily, you can so easily think yourself, "Oh, I don't really want to get up today. I'll just have a day in bed. I'll have a day in my nightie" and then that day will go to the next day and the next day"*
>
> *"You can so easily let things slide and, as you get older, it's harder then to pick yourself up again… And each time, you know, I've fallen and that, it's been that little bit harder to pick myself up again."* (Yvonne)

Yvonne appears to be referring to the physical impact of reduced activity on the body, but also the relationship between activity levels, motivation, and emotional well-being. Reduced activity levels and low motivation can be associated with low mood and depression among elders (Lampinen et al., 2000). Receiving domiciliary care appeared to reduce the possibility of this downward spiral occurring, and support both physical and emotional health.

> *"you could stay in bed or stay in your nightie, but you <u>don't</u>. Because you know they're coming and they're gonna help you"* (Yvonne)

Participants similarly described that the emotional support carers provide is an important factor in enabling them to "carry on" with life. For example, Peter shared:

> *"I could live without the carers. My body could live without the carers as well, but whether my head could live without the carers, I don't know."* (Peter)

For Peter, the emotional support his carers provide is positioned here as fundamental to his psychological well-being. He questions how his mental state would be affected without their presence. Peter describes how, even though he feels confident in attending to his own physical needs, he depends on his carers for his mental health. Peter's statements below demonstrate how, for some elders, this emotional support may be equally or more valuable to them than support with their physical needs.

> *"I think you know, from the psychological point of view, it's exceptionally important. I would stress to anybody that it's as important as the bed making, the food making, the showering and all the rest of it, because if you haven't got friendship…you haven't got a lot left really, so that's great having somebody coming in and doing the jobs. But you <u>need</u> the mental well-being as well, you need to feel mentally well. You need to feel that you're not depressed and these guys* [the carers] *never ever would never ever let me get depressed."* (Peter)

Peter is highlighting the importance of domiciliary care attending to, and valuing, both the mind and the body and powerfully portrays that support for both is required to “carry on” with life. Participants’ accounts suggest that the relationship formed with carers, when receiving care for the first time, is what prevents them from giving up on life.

3.5. Who Am I Now? Changing View of Oneself

The second overarching theme, ‘Who am I now? Changing view of oneself’, was constructed to present how receiving domiciliary care for the first time was described as a significant life change, prompting participants to reconsider how they view themselves and the person they believe themselves to be. Participants described how receiving domiciliary care for the first time prompted a realisation of their advancing age, declining abilities, and the limitations to daily life they now experience. These realisations led to recognition of parts of the self which were lost, yet also parts which remained the same. This overarching theme encompasses two themes: ‘Struggling to accept the need for help’ and ‘Lost parts of the self’.

3.5.1. Struggling To Accept The Need For Help

This theme explores the core pattern of meaning, expressed throughout the interviews, that accepting that one now needs care can be extremely challenging and evoke a change in how elders view themselves. Participants appeared keen to maintain control and independence where they could and for as long as possible. Accepting the need for care was described as a process, and a process which remained ongoing for many.

In the participants’ accounts, domiciliary care was presented as something they had never expected to need. Participants described feelings of shock, which made receiving domiciliary care for the first time harder to come to terms with.

> *“all of a sudden, you've gone from being completely independent, never thinking about having care, to realising that you've got to accept care. Otherwise your whole life changes completely.”* (Yvonne)

Yvonne’s description portrays the sense of suddenness and shock many participants described experiencing when first realising they needed care. The participants appeared to feel that the time between being fully independent and needing care had passed very quickly. Yvonne also describes the pressure to accept the need for care quickly, to prevent further life changes. This was understood to mean significant deterioration in health and ability or the potential need for residential care.

Many participants expressed believing that they would continue to live independently until they died. When asked whether having care was something he had expected at this stage of his life, Oliver reported, “*No. I just expected to die*.” This suggests that ideas of dependence or the need for help are so far removed from individuals’ views of themselves, and hopes for their lives, that they are not considered a possibility. It may be that this possibility feels intolerable and therefore contemplation of it is avoided. Participants’ accounts could suggest that death is easier to consider.

> *“I thought I was going to go on, as I was, for well, till the end of my days. I'd never never thought that I would end up needing or not having my full independence, but, you know, none of us know what's gonna happen, do we? None of us know what's around the corner.”* (Yvonne)

As Yvonne articulates, the need for domiciliary care was presented as something unexpected and not in participants’ preferred life plan. For elders, the need for care may prompt recognition of their advancing age and mortality. Louise shared, “*Well, it makes you conscious that we're all mortal, I think.*”

> *“and in terms of my longevity, which is extremely minimal and I know I'm on the end of a very steep slope and I'm at this end and there's not much.*

> *There's no crawling back anymore. No recovery. But you know, I'm resigned."* (Neil)

Whilst speaking about his care, Neil shared believing that recovery or improvement does not feel possible at this point in his life. Such accounts could suggest that accepting the need for care for the first time is difficult because it signifies movement towards the end of life. Yvonne reported that, "*you realise that life is slipping away from you.*" Participants' accounts suggested that receiving care for the first time acts as a signifier of both the changes to their lives, including their physical limitations, and their proximity to death.

Participants shared that accepting that they needed to have care for the first time was a process, and it was hard to let go of the past.

> *"But when you've been used to doing things for yourself and encouraged to do things for yourself, it's hard to let go. I still find it hard to let go sometimes after all this time. I really do."* (Mary)

Mary's description suggests that having care for the first time had required her to change life-long behavioural patterns. Allowing herself to be cared for conflicted with how she had always been encouraged to behave. This encouragement may have come from particular figures in Mary's life and from societal narratives valuing independence. Mary also related the difficulty in accepting help to finding it hard to trust other people.

> *"I think … the biggest lesson you've got to learn is to trust people. And to hand over the running of your life to somebody else, and that's the biggest and hardest thing to do."* (Mary)

Mary's account indicates that she has had difficulty trusting others in the past and demonstrates the complex task carers face to adapt their care to the specific psychological state of each elder, according to their personal background. Trusting carers with one's life was presented as difficult, particularly when participants were used to being independent and feeling in control. Accepting care for the first time appeared to necessitate accepting a reduced sense of control over one's life.

Participants appeared to be at different stages in this process of accepting the need for care, with some participants denying that they needed help. It was noticed that this was expressed more commonly by the male participants.

> *"Yeah, I could pick up the phone now, ring [Care provider name] and say look I don't need them anymore."* (Peter)
>
> *"Really, they're just putting the eye drops in that which I can do myself quite comfortably, but it makes sure they are being done at the right times."* (Finley)
>
> *"I'm even right even now I'm quite positive I could live alone."* (Neil)

Despite stating that they did not need the help, these participants all expressed appreciation for the care they received. For example, Peter shared, "*I don't need them to come. But I <u>want</u> them to come*." Although it is possible that a carer is not needed, it could also be that wanting care may be an easier explanation for some elders to tolerate than needing care.

Participants' accounts suggested that accepting that they needed to start receiving care could be particularly difficult because it challenged their view of themselves.

> *"For me, you know. You know, what was I doing? I mean, having some woman, you know, having to bloody wash me and showering me and wash my hair and shit, what have I come to, you know? What is this? Is it, is this what I've got to look forward to?"* (Peter)

Peter outlines that being a person who needed care, particularly assistance with washing, was different to whom he saw himself to be, leading to feelings of anger, shame and despair. These feelings are presented as difficult to tolerate, demonstrating the emotional significance of needing care for the first time.

Peter's account suggests some feelings of disgust towards himself, which may relate to the negative perceptions of ageing and dependence in UK society. Peter also outlines fears for the future, "*is this what I've got to look forward to?*", which may link to fears about the person he feels he is becoming: an identity which conflicted with his own at the time.

3.5.2. Lost Parts Of The Self

This theme explores the core pattern of meaning, expressed throughout the interviews, that how participants viewed themselves had changed since beginning to receive domiciliary care, with a sense that parts of themselves had been lost. Some participants described themselves as useless and different, and shared missing their past life and abilities.

It was noticed that participants frequently spoke about their past occupations, knowledge and skills throughout the interviews. Participants appeared keen to portray a sense of who they once were, and how the limitations they now experienced in daily life conflicted with this.

For some participants, these changes to their lives and abilities were presented as extremely painful. Oliver shared that, upon first leaving hospital, he told his family he would prefer to die rather than live as an "*invalid*". He explained:

> *"Well, I'd been used to working hard all my life. All of a sudden, I was a fuckin' invalid. ((Pause)) And I don't, don't like being an invalid."* (Oliver)

Oliver describes here how the person he felt he had become conflicted with the person he felt he was and wanted to be. He describes himself harshly, suggesting deep feelings of anger, shame and unhappiness related to his limitations and reduced feelings of self-worth. The prospect of being an "*invalid*" had felt so intolerable that he had wished to die instead.

Participants described losing parts of themselves they identified with and valued. Doreen reported:

> *“All my life I've … been able to put things back for what I've received. You know, I've been [job title] of this and all the rest of it, and erm, now I feel pretty useless to be honest.”*
>
> *“all I'm doing is taking I'm not putting anything into life anymore.”*
>
> *“I think that's what we're here for, to look after each other.”*
> (Doreen)

For the participants, thinking about their care appeared to be a gateway to thinking more widely about their lives. Doreen’s account suggests that, prior to needing care, she viewed herself as someone who contributes to society and the lives of others, such as via employment. It appears that now Doreen feels unable to make the same contributions, her view of herself has changed, with her now considering herself “*pretty useless*”. Doreen feels she has lost her purpose in life (“*to look after each other*”). This is significant in suggesting that, for some elders, their sense of self-worth may be tied to their ability to contribute to the economy or family life. Louise reported feeling that she has lost the ability to fully provide for herself and her husband, as they require carers to prepare meals. She described how, to her, having carers is a way of “*repairing*” this:

> *“*[Life] *is different because. At the same time, I'm repairing. I'm repairing what I can't provide myself.”* (Louise)

Participants reported missing their past life. This is evidenced in their accounts, but also in the extent to which participants spoke about their past during the interviews and described doing so with their carers.

> *“Because I can't see, and I can't hear… I miss everything and my life has changed tremendously. And I'm very upset with it all. And I don't know quite what to do about it.”* (Finley)

The transition into receiving care appeared to lead the participants to reflect on their overall life circumstances. Participants’ accounts suggested that the changes to their lives were experienced as losses, such as loss of abilities, occupation and independence. These changes were presented as significant and upsetting for participants and some were considered irreversible (“*I don't know quite what to do about it*”*),* creating feelings of hopelessness.

Since needing to receive domiciliary care for the first time, multiple participants described viewing themselves negatively because of the limitations to their abilities. Examples include:

> *“I don’t do a bloody thing. I'm a lazy bastard”* (Oliver)
>
> *“As I say, I’m a lazy so-and-so, so I can sit and watch the television”* (Mr Zebedi)

This self-criticism appeared to be associated with valuing independence, with the need to begin receiving care signifying a loss of the independent part of themselves. This change in the way participants viewed themselves impacted them emotionally. For example, Mary described needing support to get out of bed as a “*Horrible feeling. I felt so helpless and it's a feeling I don't like*”*.* Oliver described feelings of misery:

> *“I’m a miserable old sod, I suppose. I don't like people helping me. I like to feel that I can do it myself.”* (Oliver)

With the feeling that they had lost parts of themselves and their identities, the participants described a sense of losing control over their lives.

> *“you feel, all of a sudden, you're losing grip on your own life. It’s, a lot of the things that you did are being taken away from you.”* (Yvonne)

This description of “*losing grip on your own life*” could imply that elders are led to question who they are and what their life is for, upon receiving domiciliary care for the first time. Yvonne’s account portrays a sense of fear, loss and helplessness, which appeared to be associated with experiencing a reduced sense of control over her daily life.

4. DISCUSSION

4.1. Chapter Overview

This chapter opens with an overview of the research findings. The findings are examined in relation to the existing literature, and strengths and limitations of the study are discussed. Implications for research and practice are identified. The chapter closes with my personal reflections and a conclusion.

4.2. Overview of Research Findings

This study explored elders' accounts of first receiving domiciliary care. The findings provide a greater understanding of elders' experiences of this transition, which is an important step towards improving the quality of care elders receive and supporting the well-being of those being cared for.

The first research question examined how elders describe their experiences of first receiving domiciliary care. Receiving domiciliary care for the first time was described as a fundamentally relational experience and a significant life event, which elicited reflection on one's life and identity. Domiciliary care was experienced as an alternative to giving up on life, yet, for several participants, it was initially unwanted, feared and resisted. Friendship-like relationships with carers provided the foundation which enabled domiciliary care to be an acceptable and enjoyable experience, which supported the participants' psychological well-being.

The second research question explored how elders view themselves since receiving domiciliary care for the first time. Some participants spoke critically of themselves since first receiving domiciliary care and felt that parts of their identity had been lost. The changes in the participants' abilities impacted their perceptions of their self-worth. Carers' support encouraged the participants to continue to value themselves and their lives, despite these changes.

4.3. Discussion of Research Findings

In accordance with the critical realist stance of this research, the findings represent my interpretations of the participants' subjective experiences. Each reader will examine these findings through the lens of their own unique context.

4.3.1. How do elders describe their experiences of receiving domiciliary care for the first time?

Elders' descriptions of their experiences centred on the relational and psychological aspects of receiving domiciliary care for the first time. The participants described their experiences of first receiving domiciliary care as dependent upon the relationships they formed with their carers. These relationships were experienced as friendships. Receiving domiciliary care for the first time was described as a significant life event and a difficult transition which involved a process of acceptance. Elders also described their experiences as life-enhancing and supportive of their emotional well-being.

4.3.1.1. A relationship akin to friendship

Existing research has pointed to the importance of the relationship formed between elders receiving domiciliary care and their carers (Healthwatch England, 2017; S. Hughes & Burch, 2020; Sykes & Groom, 2011), which the current study's findings support. For example, Sykes and Groom (2011) identified that elders' positive experiences of receiving domiciliary care focused upon the relationships they had formed with their carers. Respect, rapport and trust have been named as important features of the caring relationship (CQC, 2013; EHRC, 2011; Healthwatch England, 2017; Sykes & Groom, 2011) and were also identified by the current study's participants.

Elders' characterisation of their relationships with their carers as friendships is a key finding of the current study. This finding extends the existing research to highlight the importance of experiencing a sense of friendship with one's carers when accepting care for the first time. Participants expressed deep affection towards their carers. For example, some shared feelings of love or equated their carers with family members. Other studies have named a sense of friendship as occurring (S. Hughes & Burch, 2020; Sykes & Groom, 2011), yet have not explored the potential reasons for this understanding of the relationship, or its meaning, in depth. No previous studies have identified the experience of friendship explicitly in relation to receiving domiciliary care for the first time. Participants in this study repeatedly characterised the relationship they had with their carers as a friendship, which was interpreted as a known and uncomplicated relationship type. It appeared that classifying the relationship in this way not only demonstrated participants' affection for their carers, but enabled them to accept care into their lives more easily. This appeared to be because the participants positioned themselves as peers to their carers, rather than dependent upon them.

Authentic human relationships were fundamental to the participants' positive experiences of receiving domiciliary care for the first time. This finding is in accordance with the theory of human caring (Watson, 1979, 2009), which conceptualises caring as a way of being, and promotes personal connection between caregiver and recipient. As the theory explains, effective caring takes place when the relationship attends to the whole person and goes beyond the objective care needs. Caring that attended to the whole person was evident in the participants' accounts, which centred on descriptions of the psychological and relational aspects of their care and care that went beyond their stated needs (e.g., food preparation). It appeared that carers were not simply delivering the care tasks but making a personal connection with the elder, such as by sharing details of their own lives. These personal elements were symbolic of friendship to the participants. The current study emphasises that the human elements of the relationship are those which supported elders to accept their need for help and enjoy receiving care, rather than resisting it.

Therapeutic relationships seem central to experiences of both domiciliary care and psychological therapy. Psychotherapy research has identified that the therapeutic relationship, and factors such as warmth and empathy, account for the highest variance in clinical outcome (Lambert & Barley, 2001). It has been suggested that the relationship provides the foundation for supporting others

(Lambert & Barley, 2001). The notion of the relationship as the foundation in psychotherapy appears parallel with the role of the relationship in domiciliary care. For example, the relationships between elders and carers (in the current study) seemed to enable elders to accept, embrace and enjoy receiving domiciliary care for the first time. In an extension to the previous research identifying the importance of relationships in domiciliary care (Healthwatch England, 2017; S. Hughes & Burch, 2020; Sykes & Groom, 2011), this study emphasises that the relationship is paramount at the beginning of the process, when one first needs care. As psychological therapists are specifically trained to provide the conditions which create a therapeutic relationship, the current study’s findings suggest a potential role for clinical psychologists in providing training to carers (see 4.5.2.2.).

There are potential risks to the close, friendship-like relationships the participants valued. Professional boundaries between domiciliary carers and the elders they support are necessary for the safety of both parties. In applying the knowledge gained from this study, carers will be required to find a balance between forming close relationships with elders and maintaining the professionalism required to do their job safely and appropriately. This challenge exists across the health and social care professions. However, the personal care tasks undertaken by carers demand different boundaries in relation to physical contact compared to some other professions. Carers may also receive less training or support with navigating these aspects of their role. For example, clinical psychologists receive regular clinical supervision, in which these dilemmas can be discussed. As the previous literature highlights, instances of abuse have occurred between elders and domiciliary carers, including physical and financial abuse, neglect, and treatment which breaches elders’ human rights (EHRC, 2011). The participants in the current study admired and complimented the professionalism of their carers and yet also valued close and personal relationships. The findings, therefore, highlight the importance of further research to support domiciliary carers to balance the complex demands of their role. Greater professional distance between domiciliary carers and elders was desired by some participants in previous research (Palmer et al., 2015), providing a contrast to the current study’s findings. This difference demonstrates the importance of carers understanding elders' individual preferences and specific care needs, as well as monitoring the professionalism of their practice.

Social connection, provided by friendship-like relationships with carers, was an important aspect of the participants' experiences of receiving domiciliary care for the first time. Participants in the current study spoke about the importance of their relationships with their carers in the context of the loss of friendships which commonly occurs in older age. The current study also took place in the wake of the Covid-19 pandemic, which is likely to provide significant context to the importance of close relationships between the participants and their carers. For many elders, the pandemic was a time of prolonged isolation. Increased rates of loneliness, anxiety and depression were reported among UK elders (Robb et al., 2020). At the height of the pandemic, it is likely that the participants' care visits would have been their only opportunity for social contact. Participants also described how their relationships with their carers enabled them to feel connected to wider society. In the broader context, the current study's findings may demonstrate the importance of care relationships in reducing the marginalisation of elders who require domiciliary care.

The caring relationship appeared to have a greater impact on the participants' experiences of first receiving domiciliary care than the practical aspects of their care. Previous research has highlighted elders' concerns relating to the frequency, timing and duration of their care visits (CQC, 2013; Healthwatch England, 2017; Palmer et al., 2015; Sykes & Groom, 2011). Some participants in this study did acknowledge that these practical factors were important, but they were not foregrounded in their accounts. This could have been a consequence of knowing my mental health background or the framing of the interview questions. Participants' descriptions of receiving domiciliary care for the first time focused much more on the caring relationship and its impact on well-being and sense of self. This may demonstrate the substantial efforts of the participants' care provider to deliver care which is on time and meets their clients' needs, but may also suggest the dominant importance of the relationship when receiving domiciliary care for the first time. Based on the participants' accounts, it is important that care providers allow carers sufficient time for social interaction with the elders they support, particularly at the start of the person's care.

4.3.1.2. A significant life transition

Elders described receiving domiciliary care for the first time as a significant life event, which involved a process of adjustment and acceptance. Existing research identified that the transition into receiving care for the first time could be a disruptive and anxiety-provoking period for elders (S. Hughes & Burch, 2020; Palmer et al., 2015; Sykes & Groom, 2011). For example, Sykes and Groom (2011) identified that domiciliary care was not welcomed by some elders. In the current study, some participants actively resisted accepting their need for care, despite significant levels of need. The caring life-course theory (CLCT) recognises the significance of care transitions and offers an explanation for why some participants found care particularly difficult to accept. The theory proposes that one's capability to accept care from others can be influenced by their life experiences and their physical, cognitive and psychosocial development (Kitson et al., 2022). As the theory would suggest, some participants related their difficulties accepting care to their life experiences, such as being encouraged throughout their life to care for themselves.

The need to begin receiving domiciliary care appears to prompt a realisation of one's advancing age, mortality, and the changes one has experienced to one's life. Receiving care for the first time seems to act as a signifier for wider changes. Some participants interpreted their need for care as a sign that they were approaching the end of their life. Palmer et al. (2015) highlighted the difficulty of adapting to first receiving domiciliary care, both personally and within one's home. The current study suggests that, beyond the challenge of needing to adapt, receiving care for the first time was a time of significant realisation for participants. The prominence of death in the participants' accounts was an unexpected finding. In contrast to Palmer et al. (2015), a changing relationship with one's home did not feature prominently in the participants' accounts. However, the interview schedule did not specifically explore this.

Accepting one’s need to begin receiving domiciliary care was presented as an alternative to giving up on life. Therefore, the transition into receiving domiciliary care for the first time has the potential to significantly impact elders’ well-being. Consistent with the findings of Palmer et al. (2015), the current study’s participants described how the need to begin receiving care affected their well-being, with some participants expressing feelings of anger and shame. Erikson’s model of psychosocial development (1963) highlights the significance of life transitions to well-being. The model suggests that elders may continue to pursue personal growth, despite the changes to their lives, or may feel resigned and hopeless (Erikson & Erikson, 1998). In line with the model, participants appeared to face an internal choice between accepting their need for care or giving up on life, at the point of first requiring care. For some participants, this severely impacted their well-being, with one participant expressing that he had initially told his family that he would prefer to die than live as an invalid. The potential for hopelessness and despair in relation to the transition into receiving care for the first time indicates the importance of elders receiving emotional support during this period. As the study’s findings highlight, the participants received support through the relationships they formed with their domiciliary carers.

Receiving domiciliary care for the first time appeared to elicit participants’ reflections on their lives, and evaluations of their lives as a whole. Similar to the realisations outlined above, the need to first receive care appeared to prompt these reflections, suggesting the significance of this transition for elders. This finding is, again, in accordance with Erikson’s model of psychosocial development (1963), which suggests that old age is a time of reflection and evaluation. According to the model, acceptance of one’s life is associated with improved well-being, and elders can experience states of both integrity and despair. In the current study, participants who expressed greater acceptance of their need for care described the positive impacts on their well-being. The participants who seemed to find accepting care more difficult appeared to experience feelings of despair, shame and disgust. This is consistent with Erikson’s model and international research which reported that elders receiving domiciliary care were happier upon reaching acceptance (Hvalvik & Reierson, 2011). The later-added ninth stage of Erikson’s model appears to be particularly relevant to this study's findings, as it acknowledges how elders' changing capabilities prompt re-evaluation of aspects of life including autonomy, shame and identity (Erikson & Erikson, 1998). The impact of first receiving domiciliary care on participants' views of themselves will be explored in section 4.3.2.

4.3.1.3. Life-enhancing support

The participants' accounts suggest that receiving domiciliary care for the first time can enrich and enhance the lives of elders. For example, domiciliary care provided participants with the opportunity and confidence to do more (e.g., leave the house) and promoted their psychological well-being. Despite their physical difficulties, the participants spoke about the mental health aspects of their care. The current study's findings emphasise the potential positive impact of receiving domiciliary care on elders' mental health. The transition into receiving care can be highly challenging for elders, as outlined in section 4.3.1.2. However, this study's participants suggested that domiciliary care can provide elders with the emotional support necessary to continue with life, rather than giving up. This finding goes beyond the previous literature which identified that domiciliary care could support emotional wellbeing (EHRC, 2011; S. Hughes & Burch, 2020; Sykes & Groom, 2011). Participants generally attributed the improvements in their well-being, confidence, and activity levels to the relationships they had formed with their carers (see 4.3.1.1.), rather than the practical support they received. Therefore, the current study would support the statement made by S. Hughes and Burch (2020) that it is not domiciliary care itself which supports autonomy, but the way in which the care is given.

The current study's findings suggest that receiving domiciliary care can support elders to increase their activity levels and functioning, or act towards preventing ongoing decline. The findings highlight the combined role of the emotional and physical support domiciliary carers can provide. Domiciliary care cannot prevent a decline in its entirety, yet the findings suggest that care can promote factors such as motivation and confidence, which subsequently impact functioning. Ryburn et al. (2009) state that older people can become "entrenched in a 'sick role'" (p. 226), associated with feelings of dependency and a lack of motivation.

They emphasise that care can support elders to restore function and increase their activity levels and independence. The current study's participants presented their care as support which actively prevented a 'sick role' from forming. Participants spoke about being supported to maintain their appearance, get dressed, and take part in valued activities, which they understood to prevent physical and mental decline. The participants' accounts challenge stereotypes associating old age with progressive dependency and decline (Centre for Ageing Better, 2021). Additionally, the findings support existing literature suggesting that care services can empower elders, such as facilitating greater confidence and autonomy (Thompson & Thompson, 2001). Knowledge of these findings could enhance public perceptions of care and improve elders' attitudes towards receiving domiciliary care for the first time.

4.3.2. How do elders view themselves since receiving domiciliary care for the first time?

Receiving domiciliary care for the first time appears to elicit changes in how elders view themselves. For example, some participants shared self-critical views of themselves as useless and lazy, in the context of the changes to their abilities which necessitated care. Existing research has identified that domiciliary care can impact upon elders' sense of self (S. Hughes & Burch, 2020). The current study's findings offer clear support for this and further indicate that changes to sense of self can occur in response to needing to receive domiciliary care for the first time. The theory of Gerotranscendence (Tornstam, 1989) recognises that how individuals view themselves and the world can change with age. The findings of the current study would support that changing views of the self can occur in older age and that elders' worldview shifts away from the materialistic and towards the spiritual, in accordance with the theory. The participants' accounts were reflective and emphasised the meaning and impact of their experiences, above the material changes.

The participants' accounts suggested that their need for care led them to question their identity, and they described believing that parts of themselves had been lost. For example, one participant perceived that they had lost their ability to contribute to the lives of others and expressed reduced feelings of self-worth. Supporting others had been an important aspect of their identity throughout their working life. The Roy adaptation model (RAM) would suggest that the participants were experiencing difficulties in the self-concept and role function modes of adaptation, which impacted their psychological coping (Roy, 2009). The self-concept mode encompasses aspects of identity, including how individuals view themselves. The role function mode comprises the individual's roles in society, which the model states provide social integrity (Roy, 2009). For the current study's participants, changes in identity appeared to be closely linked to changes in roles, such as in the example provided above. In addition to experiencing some losses of role, RAM would suggest that the participants were adapting to the role of being cared-for. As previously outlined (4.3.1.2.), this transition was extremely emotionally challenging for some participants. RAM would indicate that carers can promote elders' adaptation, which the current study's findings support. For example, one participant described how her inability to prepare meals for her husband had been upsetting for her, yet, receiving domiciliary care to support with meal preparation provided a way of solving this. The findings promote supporting elders receiving care to continue to enact their valued roles. A further potential example could be a carer assisting a grandmother to make a phone call to her grandchild.

Changes in how elders view themselves when first needing care appear to make it more difficult for them to accept care into their lives. The current study adds to existing research identifying that domiciliary care can impact elders' sense of self (S. Hughes & Burch, 2020) to suggest that this change can be part of the reluctance or resistance some elders display towards receiving care. Existing research has suggested that the negative perceptions of dependence in UK society may encourage self-critical views when people find themselves in need of support (Peacock et al., 2014). Elders have also shared how negative stereotypes of ageing can lead them to avoid accessing services (Hoban et al., 2013). In the current study, some participants described how accepting care can alternatively be understood as a demonstration of self-respect and a commitment to maintaining their standards of living. Therefore, it appears to be important for carers to support elders to maintain feelings of self-worth and positive views of themselves, rather than internalising critical narratives upon needing to receive domiciliary care for the first time. The participants shared examples of carers providing this support, such as being non-judgmental and supporting their participation in valued activities.

Participants' perceptions of themselves since needing to receive domiciliary care for the first time appeared to have a greater impact on their well-being than the objective changes to their abilities. This finding is consistent with existing longitudinal research (Rudinger & Thomae, 1990), which suggests that how elders perceive themselves and their lives has a greater impact on their emotions and behaviour than the objective situations they encounter. RAM also suggests that one's self-concept can influence both physiological and psychological coping (Roy, 2009). In the current study, participants with seemingly lower levels of need described significant changes to how they viewed themselves and their lives. One participant required care only once per week but described himself as lazy and an invalid. The participants expressed that the relationships they formed with their carers could encourage more positive views of themselves and improve their feelings of self-worth. This finding is consistent with previous research which highlighted that how domiciliary care is delivered impacts whether one's sense of self is threatened or supported (S. Hughes & Burch, 2020). The current study adds that the way in which care is provided at the outset of receiving domiciliary care appears to be particularly important for one's sense of self and well-being. For example, the participants suggested that the way care is delivered can influence whether elders accept their need for care, and feel supported to continue with life, or feel like giving up. To improve elders' well-being and experiences of care, these findings would suggest that assessments of care quality should evaluate not just whether elders' needs have been met, but how elders feel about themselves.

4.4. Critical Review

This review of the research has been informed by the four dimensions of qualitative research quality reported by Yardley (2000, 2008, 2017): sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance, and the guidance for undertaking high quality reflexive TA (Braun & Clarke, 2021b, 2023).

4.4.1. Strengths

As the first UK study to specifically explore elders' first experiences of receiving domiciliary care, this research contributes new knowledge to the field. Using qualitative methodology, this research has focused specifically on the perspectives of elders themselves, rather than the perspectives of carers or family members, which are more abundant in the UK literature. This study has also looked beyond quality and satisfaction to provide deeper insight into elders' personal and psychological experiences of receiving domiciliary care for the first time.

A key strength of this study is that elders were interviewed in their own homes, which indicates *sensitivity to context* (Yardley, 2017). Interviewing participants at home allowed elders to participate who would have otherwise been excluded. For example, Finley's hearing and visual impairments would have excluded him from a video call interview. By nature of the need to receive domiciliary care, many of the participants rarely left their homes. One participant chose to be interviewed whilst in bed, which being at home allowed, as they would have been uncomfortable sitting for the duration of the interview. Large print materials and an information video were also provided to support inclusion.

The study utilised broad inclusion criteria with the aim of minimising unnecessary exclusion. For example, I did not impose an upper age limit or 'blanket' restrictions related to diagnoses (e.g., dementia), with the aim of enhancing transferability of the findings. The concept of transferability was formulated by Lincoln and Guba (1985) and can be defined as "the extent to which (aspects of) qualitative results can be 'transferred' to other groups of people and contexts" (Braun & Clarke, 2013, p. 282). Situating the sample, such as providing information about the participants' demographics and care needs (Table III), also enhances transferability (Elliott et al., 1999). I have attempted to balance protecting the participants' anonymity with providing sufficient information to illustrate context and allow transferability.

To support *transparency and coherence* (Yardley, 2017), a clear account of the study's data collection and analytic procedures are provided in chapters two and three. Additional information is also presented in the appendices to demonstrate the research process.

4.4.2. Limitations

By nature of the difficulties of finding a domiciliary care provider willing to support recruitment to the study, all of the participants were supported by one domiciliary care provider, an independent company with an 'outstanding' CQC rating. This means that all participants were recruited from one geographical location and there is a lack of socio-economic diversity, as all participants could afford private domiciliary care. The provider's 'outstanding' rating is representative of the high-quality care they deliver; therefore, the experiences of elders receiving care from providers with lower ratings may differ from those of the current participants. The challenge of recruiting a domiciliary care provider to support the study is a finding in itself. I wondered whether most domiciliary care providers felt too stretched to consider supporting research or were wary of criticism. Given the considerable demands on the state-funded sector, it is likely that future research may also predominantly rely upon collaboration with care providers offering privately funded care, a sector which is expected to grow (UKHCA, 2021). A longer process of building relationships with care providers, which this study's timeframe did not afford, could improve the likelihood of collaborating with providers offering state-funded care.

Whilst the sample encompasses an equal number of males and females and a range of ages (76-95 years), all participants identified as White and either British or English. The lack of ethnic diversity may limit the transferability of the findings to other ethnic groups and minoritised cultural backgrounds. As explored below (4.5.1.), elders from racialised backgrounds or identifying as lesbian, gay, bisexual, transgender, queer/questioning, intersex or asexual (LGBTQIA+) may have different concerns and experiences when receiving domiciliary care for the first time, which this study was unable to explore. Future research could be improved by collecting data on participants’ self-identified sexuality and through focused recruitment of elders from marginalised backgrounds and of minoritised identities.

As Palmer et al. (2015) highlight, there are challenges to reliable data collection when researching domiciliary care. Elders may be fearful of losing the services they rely upon if they express negative views. Alternatively, elders may accept poor quality care as the norm. In this study, the participants were aware that I was collaborating with their care provider and may have been reluctant to share dissatisfaction or criticism. To encourage honesty, I assured participants of the measures in place to maintain confidentiality and highlighted the potential impact of the study’s findings. However, the likelihood that concerns about losing services influenced this study’s findings is small, given that participants were self-funding their care and could employ a different provider.

Potential participants were identified by the care provider. It is possible that the care provider may have selected participants who were more likely to express positive views of the care they were receiving. This method of selection may have limited the range of experiences shared in the interviews. However, in my discussions with the care provider, they appeared to be very interested in learning more about supporting clients who are reluctant to begin receiving care. The participants’ accounts provided both positive feedback and expressions of the challenges they had faced, and it, therefore, appears unlikely that the participants were purposefully selected to give favourable accounts. Even when potential selection bias is acknowledged, the care provider would find it challenging to predict the responses of their chosen participants. Nonetheless, future studies could be advertised more widely (e.g., in the care provider’s newsletter) to provide the option for potential participants to self-select.

Notably, this study focused on exploring elders' experiences of receiving domiciliary care for the first time, yet the participants had already been receiving care for an average of 3.7 years. There were no exclusion criteria based on the duration of domiciliary care, which could be considered a limitation since participants might have faced challenges recalling their initial experiences. However, retrospective accounts offer participants the opportunity to reflect on the significance of their experiences over time, enabling them to provide more comprehensive and coherent insights into what they ultimately found meaningful. For instance, participants described the ways in which their relationships with their carers developed over time, details which would not have been gained if participants had been recruited within their first few days of receiving care. However, capturing elders' initial responses to receiving domiciliary care within the first weeks and months (i.e., "as it is happening") could be an interesting and useful focus for future research and enable exploration of whether elders' reactions differ over time.

4.4.3. Use of Reflexive Thematic Analysis

Reflexive TA, and other qualitative methods, are criticised for their subjectivity, which is said to lead to individualistic results that may be difficult to transfer across contexts (Morgan, 2022). Subjectivity is embraced as a valuable resource in reflexive TA (Braun & Clarke, 2021c; Gough & Madill, 2012) and I invite the reader to consider their own interpretations of the data. To enhance the research quality, I immersed myself in the literature related to TA throughout the planning, conducting and reporting of this research.

In addition to the examples of good practice named in Chapter 2 (see 2.9.3.), I strived to ensure that the findings were generated by a coherent and reflexive analysis. The analysis presents a balance of data extracts and analytic commentary (Chapter 3), in accordance with published guidance (Braun & Clarke, 2021b, 2023). Data extracts illustrate how my interpretations were grounded in the data (Elliott et al., 1999) and, therefore, how the themes generated display *sensitivity* to the specific dataset (Yardley, 2017). Themes were repeatedly revised and reviewed to prevent the reporting of topic summaries and honour the richness of the participants' accounts. Furthermore, the themes give rise to "actionable outcomes" (Braun & Clarke, 2021b, p. 345), which will be outlined in section 4.5.

Throughout the research process, I have been committed to adopting a reflexive approach. I was transparent with the participants about my interest in the subject area and situated myself, my personal and professional experience, and hopes for the research during introductions. Use of supervision and a reflexive log have supported me to reflect upon my active role in shaping this research, as evidenced throughout this report (see 1.2. and 2.9.4.). I provide concluding reflections in section 4.6.

4.5. Implications and Recommendations

4.5.1. Implications for Research

To my knowledge, this is the first UK study to specifically explore elders' experiences of receiving domiciliary care for the first time. This study has found that receiving care at home can affect how elders see themselves and how they feel emotionally. It adds to the existing literature by showing that receiving domiciliary care for the first time has personal and psychological importance for elders. The study has identified ways in which elders characterise and experience receiving domiciliary care for the first time, the importance of the caring relationship during this time period, and how the need to first receive domiciliary care impacts upon how elders view themselves.

Pertinent to the study's findings is elders' characterisation of their relationship with their carers as a friendship. The findings suggest that elders highly value close, friendship-like relationships with carers. In providing these relationships, there is potential for carers to face dilemmas related to maintaining professional boundaries. The social care literature identifies the nuances of personal and professional boundaries as a complex, yet under-researched area (Pugh, 2007; Reimer, 2014). Further research into how domiciliary carers navigate this challenging task could provide beneficial clarity and guidance for carers. This guidance could inform professional guidelines or working practices for individual care providers. For example, focus groups with domiciliary carers may provide an understanding of how carers navigate dilemmas around confidentiality or personal security, and identify boundaries they set for themselves. A case study approach (e.g., of the relationship between an elder and their carer) may also be worthwhile, as could provide in-depth information useful to the complexity of this area.

This study has explored elders' experiences of receiving domiciliary care for the first time. However, elders are not a homogenous group. As this study indicates, elders' unique past experiences will inform their relationship to first receiving domiciliary care and their experiences. Constraints of this study's sample did not allow for exploration of the experiences of marginalised groups, such as elders from racialised backgrounds or elders identifying as LGBTQIA+. A systematic review examining the perceptions of LGBTQIA+ people aged 60 and over of receiving home care services (not specific to domiciliary care) identified fear at the prospect of accessing these services because of the perceived risk of homophobia (Smith & Wright, 2021). Some participants reported that they would attempt to conceal their sexuality if professionals visited their home. The systematic review identified just one UK study (Willis et al., 2018), which was not specific to domiciliary care, and offers a prospective account. Hearing the accounts of racialised and LGBTQIA+ elders who are receiving domiciliary care for the first time could support professionals to understand the specific needs of these groups during this transition. Professionals can then learn from what works, from these elders' personal experiences.

Consistent with previous research (S. Hughes & Burch, 2020; Palmer et al., 2015), the current study's findings support the use of qualitative methodology to explore elders' experiences of domiciliary care. This research provides a depth of knowledge that satisfaction measures would not have captured. Additionally, I would advocate for face-to-face interviewing which takes place within elders' homes. The Covid-19 pandemic introduced a new era of remote interviewing via video call and telephone, which would have excluded many of this study's participants. If willing and able participants are unfairly excluded, this could constitute unethical research practice (BPS, 2021).

The challenges experienced by the domiciliary care sector necessitate examination of cost-saving and quality. However, this study's findings would advocate for future research evaluating domiciliary care services to also consider the extent to which the care provided addresses elders' social and psychological needs.

4.5.2. Implications for Practice

This study has implications for the practice of health professionals, carers, care providers and commissioners.

4.5.2.1. Supporting elders

Discussions with elders about the need to begin receiving domiciliary care take place with various professionals (e.g., care managers, carers, occupational therapists, social workers, psychologists, hospital discharge coordinators etc.), at home and in clinical settings. For example, hospital occupational therapists may introduce domiciliary care as part of discharge planning conversations. Based upon the findings indicating the psychological significance of receiving domiciliary care for the first time, I recommend that professionals adopt a compassionate and curious approach to engaging in these discussions. For example:

- Acknowledge that receiving domiciliary care for the first time is a significant change and may not have been something the person had thought about before or hoped for.
- Listen to fears and worries, acknowledge these as understandable, and consider how these can be addressed practically, rather than providing minimising responses (e.g., "It won't be as bad as you think").
- Normalise feelings of loss, shame and anger, to demonstrate understanding of the significance of receiving care for the person.

For carers and care providers specifically, the findings suggest the importance of understanding and respecting elders' boundaries when negotiating tasks and roles. For example, carers can learn which tasks elders are keen to continue independently and be supportive of this. The findings also promote supporting elders to undertake activities associated with roles which are important to them (e.g., wife, grandfather).

For clinical psychologists working with elders receiving domiciliary care for the first time (e.g., in older adults' mental health teams or clinical health psychology services), the findings suggest the potential utility of identifying elders' values and supporting values-based action, such as via Acceptance and Commitment Therapy (ACT; Harris, 2019). ACT can also promote self-compassion and acceptance of one's emotions, and support sense of self (Harris, 2019). As some participants reported self-criticism and a loss of valued abilities, ACT may provide relevant support for elders first receiving domiciliary care.

4.5.2.2. Consultation, training and supervision

Given the potential for receiving domiciliary care for the first time to impact upon psychological well-being, the study's findings indicate the importance of closer working relationships between care providers and mental health professionals. For example, clinical psychologists have the skills to provide training or consultation to care providers and health professionals relating to supporting the emotional well-being of elders during this transition. Yet, to my knowledge, this rarely occurs within current service structures. From my experience, there can be a reluctance to fund training in areas which are considered to be additional to professionals' primary roles. However, this study's findings suggest that providing emotional support is fundamental to effective caring.

The findings also highlight a potential role for clinical psychologists in providing training to carers aimed at developing therapeutic relationships. However, it is debated whether these skills can be taught or whether some people possess natural helping abilities (Perlman et al., 2023). Carers may have pursued a caring career because they are "natural helpers" and already have the skills to support others (Stahl & Hill, 2008, p. 290).

Peer supervision or reflective practice spaces could provide useful opportunities for domiciliary carers to discuss dilemmas and challenges relating to professional boundaries and the close relationships they form with the elders they support. This would be in acknowledgment of carers' professional responsibilities and that such close relationships create the potential for caring to have a significant emotional impact on carers (e.g., following a client's death).

4.5.2.3. Service provision and commissioning

The participants' positive experiences of care, which supported their well-being and enhanced their lives, were associated with the *way* in which care was provided and the relationships formed with carers, not the completion of objective tasks. Informed by this study, I therefore share the concerns raised about the depersonalised, task-focused approach to domiciliary care associated with time-and-task commissioning (Gethin-Jones, 2012). The study's findings highlight the need for the mental health benefits of domiciliary care to be recognised during the commissioning of services. For example, it is important that care visits are of sufficient length to facilitate conversation, emotional support, and relationship-building between carers and elders.

Existing research has identified the importance of continuity of care (CQC, 2013; Healthwatch England, 2017; S. Hughes & Burch, 2020; Palmer et al., 2015; Sykes & Groom, 2011). The current research highlights the importance of continuity particularly when receiving domiciliary care for the first time. Based on the participants' accounts, it is recommended that elders receive care from a small group of consistent carers, with whom close relationships can form.

As outlined above (4.5.1.), this study provides support for a qualitative approach to gathering feedback from elders receiving domiciliary care. This is likely to be particularly important when examining experiences or well-being. Based on the findings, I would recommend that care providers gather feedback via conversation with elders (e.g., about what they value about their care), as opposed to relying solely on performance measures or satisfaction surveys.

4.6. Reflexivity: Personal Reflections

Conducting this research has been an enriching and enlightening experience for me as a researcher. This research has led me to question aspects of my own clinical practice, but also wider aspects of the experience of ageing and societal narratives relating to the need for care. For example, what does define our self-worth? What constitutes “carrying on” with life versus “giving up”? Are our hopes for ourselves as elders consistent with our hopes for our younger selves?

As encouraged by my clinical psychology training, I applied a critical lens to the findings, such as the concept of friendship expressed by the participants. Is it problematic for clients to desire friendship? As a family member of someone receiving domiciliary care, the importance of the relationship between carers and elders cannot be overstated. As a professional, boundaries are containing and protective, yet there are grey areas. Are the boundaries always correctly placed? The dilemma is pertinent to the relationships in my own clinical work and one that I will continue to ponder, in light of the knowledge gained from this research.

It was both challenging and beneficial to hold the dual identities of researcher and psychologist. At times, I found participants’ accounts highly emotive and experienced a sense of guilt at hearing participants’ struggles but not being positioned to offer further support. I also recognise that my clinical skills may have contributed to allowing participants to feel comfortable and heard. I believe a stance of compassion and curiosity enhanced the richness of data and allowed the interview to be an enjoyable experience for participants.

I am pleased and proud to contribute a study demonstrating the value of domiciliary care. I am aware, however, that this was one of my hopes for the research. This hope could have influenced my decisions and interpretations, such as the follow-up questions I chose to ask. However, it appeared that the participants also felt that it was important to demonstrate the positive contribution of domiciliary care (As Mary shared, “*You only hear the nasty bits*”!) and this was not at the expense of sharing the challenges they faced. My impression was that the participants were keen to portray the ways in which their care had enhanced their lives and how highly they valued their carers. I believe it is important for research to identify these factors, in order to improve public perceptions of domiciliary care and care work, and ultimately enhance the care elders receive.

4.7. Conclusion

This study explored elders' accounts of receiving domiciliary care for the first time. The research questions were: 1) How do elders describe their experiences of receiving domiciliary care for the first time?, and 2) How do elders view themselves since receiving domiciliary care for the first time?

Two overarching themes were generated using reflexive thematic analysis. The first overarching theme, 'A new, important relationship', encompassed the themes 'Carers are like friends' and 'Support to continue with life'. The second overarching theme, 'Who am I now? Changing view of oneself', encompassed the themes 'Struggling to accept the need for help' and 'Lost parts of the self'.

The findings suggest that receiving domiciliary care for the first time is a fundamentally relational experience, which can enhance the lives of elders and support psychological well-being. Receiving domiciliary care for the first time represents a significant life event for elders, prompting realisation of one's age and mortality and eliciting changes to how elders view themselves. With their carers' support, elders can cherish their care as an enjoyable and essential part of their lives.

The findings have implications for research and clinical practice, including recommendations for supporting elders during this significant transition and supporting the invaluable work of domiciliary carers. I urge researchers, commissioners, policymakers and professionals to recognise and uphold the fundamental psychosocial value of domiciliary care. To exemplify this, I would like to leave readers with Mary's description of her carers:

“*they make me really feel as though I’m important and that is a <u>huge</u> thing. It really is*.”

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APPENDIX A: Literature Search Terms & Criteria

Literature Search Terms:

(“elders” OR “elderly” OR “old people” OR “older people” OR “old age” OR “later life” OR “aged”)
AND
(“homecare” OR “domiciliary care” OR “care at home”)
AND
(“experiences” OR “perspectives” OR “attitudes” OR “views”)

Inclusion Criteria:

- Studies focusing upon the experience of domiciliary care for elders
- English written

Exclusion Criteria:

- Studies focusing primarily upon home care provided by medical/health professionals (e.g., GPs, district nurses)
- Studies focusing primarily upon home care provided by informal carers
- Studies which do not focus on the elder’s perspective of their care
- Studies not based in the UK
- Studies focusing on a particular group of elders (e.g., specific medical diagnosis)

APPENDIX B: Recruitment Poster

What is it like to have care for the first time?

University of East London

My name is Bethany and I'm a Trainee Clinical Psychologist working for the NHS and studying at the University of East London.

I am doing some research to understand what it is like to have care at home for the first time.

This research is about hearing your experiences of having care in your own home for the first time.

Taking part would involve having a one-to-one conversation with me (lasting around an hour). This can take place in your own home or by video call.

Would you like to share your experience with others?

What was it like when carers started visiting your home?

Taking part is voluntary. It is completely up to you whether you would like to be involved. If you would like to take part, the information you provide will be anonymised so that you cannot be personally identified.

If you are interested in taking part, or would like to find out more, please let your care provider know. I can call or visit you to give more information and answer any questions you have.

You can also contact me directly by emailing u2075212@uel.ac.uk
I would love to hear from you.

Thank you for reading!

APPENDIX C: Recruitment Information for Care Provider Staff

Step 1: Identify eligible clients

Does your client meet these criteria?

- Over the age of 65
- Currently receiving, or previously received, care in their own home
- Able to have a conversation in English without needing an interpreter
- Capacity to consent to taking part in a research study
- No cognitive or communication difficulties which would restrict participation in an interview
- Able and willing to talk about their first experiences of having care at home

↓

Step 2: Initial conversation

Please have an initial conversation with eligible clients about the research and show them the flyer. You might decide to leave the flyer with them to read and to ask them for their thoughts about it when you next visit.

If your client seems interested, you can offer to show them the information video (optional).

↓

Step 3: Ask for permission and gather details

If your client is interested in taking part, or would like to know more, please:

- Ask for their permission for me to contact them and for their contact details to be shared with me (name/telephone number/address).
- Find out if they would like me to:
  a) Speak to them over the phone to answer any questions they have **OR**
  b) Join one of your visits to meet me in person and answer any questions they have
- Leave the participant information sheet with the client to read

↓

Step 4: Contact me to provide the client's details

Bethany Manning

u2075212@uel.ac.uk

[Telephone number] (For staff only – please do not share this phone number with clients)

THANK YOU. Your support is really appreciated.

APPENDIX D: Risk Assessment

UEL Risk Assessment Form

Name of Assessor:	**Bethany Manning**	**Date of Assessment:**	**08/06/2022**
Activity title:	**Care in my own home: Elders' accounts of receiving domiciliary care for the first time**	**Location of activity:**	**Various – Participants’ own homes or remotely via Microsoft Teams**
Signed off by Manager: **DR TRISHNA PATEL**	**Trishna Patel**	**Date and time:** **(if applicable)**	**June 2022 – September 2023**

Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of participants, etc.).
If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:

Six to twelve elders (adults aged 65+) will be interviewed by the researcher to gain their accounts of receiving care in their own homes for the first time. Participants will be recruited via a care provider who will know each participant and their home set-up well. Interviews will take place in person in participants’ own homes or remotely via video call using Microsoft Teams, depending on each participant’s needs, preference and risk assessment. Interviews are expected to last approximately 60 minutes.

Overview of FIELD TRIP or EVENT:

N/A – Research study

Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

Hazards attached to the activity

Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures required (if any)	Final risk rating
Environmental risks associated with visiting participants' homes	Researcher	Homes have been risk assessed by the care provider. Risks associated with each participant's home set-up will be discussed with the care provider prior to visiting.	1	1-2	1-2	If necessary, a remote interview will be offered.	1

Covid-19 infection and transmission	Researcher and participants	The researcher has been fully vaccinated. Remote interviews will be conducted where appropriate.	1	1-3	1-3	The researcher will undertake lateral flow testing on the day of the interview and the interview will only proceed if the researcher tests negative. The researcher will wear a face covering and request windows are open to provide ventilation during the interview. If a participant tests positive for Covid-19, or displays associated symptoms, the interview will be rescheduled or will take place remotely. Depending on the level of risk associated with Covid-19 at the time of interviewing, the researcher may also request that participants wear a face covering and perform a lateral flow test prior to the interview.	1-2
Lone working	Researcher	The care provider has a check-in/check-out system, which the researcher will utilise. The researcher will discuss each potential participant with the care provider prior to visiting and the researcher can be accompanied to an interview, if this appears necessary or if the participant would prefer this.	1	1-2	1-2	The researcher will inform the Director of Studies (DoS) and care provider of the dates and times of interviews and contact the DoS once each interview has finished. The care provider will also be aware of the location of the interviews.	1

Interview content (Finding the interview upsetting)	Participants	Participants will be aware that the information they share is up to them. Participants may choose to discuss things they have found difficult about needing care. Participants will be offered a break or to discontinue with the interview if they show signs of feeling upset. Participants will be aware that they can stop the interview at any time, without providing a reason and without impacting upon the care they continue to receive from the care provider. Contact details for support services are provided on the PIS and debrief sheet.	1	1	1	The researcher will inform the care provider if a participant finds the interview upsetting and signpost to appropriate support services.	1

Review Date
08/06/2022

APPENDIX E: Participant Information Sheet

Version: 2
Date: 21.07.2022

PARTICIPANT INFORMATION SHEET

Care in my own home: Accounts of receiving domiciliary care for the first time

Contact person: Bethany Manning
Email: u2075212@uel.ac.uk

You are being invited to participate in a research study. Before you decide whether to take part or not, please read this information carefully. Feel free to talk with other people about the study (e.g., family or friends) before making your decision. If you have any questions, please contact me or speak to your care provider.

Who am I?

My name is Bethany. I am a Trainee Clinical Psychologist working for the NHS. I am studying at the University of East London (UEL) and this research is part of my Professional Doctorate in Clinical Psychology.

What is the purpose of the research?

This research is about hearing people’s experiences of having care in their own home for the first time. I would like to understand what it is like to need care at home for the first time, directly from the people experiencing this. I hope that the research findings will help care providers and healthcare professionals to know more about what it is like to have care for the first time, and what they can do to support people who need care.

Why have I been invited to take part?

If you are over 65 years old, have carers visit your home (or did so in the past) and can have a conversation in English without needing an interpreter, you are eligible to take part in the study. If you would like to speak about what it is like to have care at home for the first time, I would love to hear from you.

It is entirely up to you whether you take part or not. <u>Participation is voluntary</u>.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to provide some basic information about yourself (e.g., your age and gender) and take part in a one-to-one interview with me. The interview will be an informal conversation between the two of us and I will ask you about what it was like for you to have carers at home for the first time.

The conversation will last approximately one hour, and we can stop or take breaks whenever you would like to. I can visit you at home for the conversation, or the conversation can take place by video call using Microsoft Teams. I will record our discussion using an audio-recording device or Microsoft Teams, so that I can listen to it again afterwards.

Can I change my mind?

Yes, you can change your mind at any time and withdraw from the study without providing a reason and with no disadvantages or negative consequences. Withdrawing from the study will not impact upon the care you continue to receive from your care provider. If you would like to withdraw from the study, please tell me at any point during our conversation that you no longer want to take part, or talk to your care provider. If you withdraw, your data will not be used as part of the research.

You can request to withdraw your data even after you have taken part, providing this request is made within 3 weeks of the interview date. After 3 weeks, I will start analysing the data and withdrawing data will not be possible.

Are there any disadvantages to taking part?

During our discussion, the information you share with me is up to you. You may want to talk about things that you have found difficult about needing care. If you are finding the conversation upsetting, we can take a break or stop our conversation at any point. The organisations below might be useful, if you would like further support.

Age UK
Support and advice for older people
Free confidential advice line: 0800 678 1602
Age UK Essex: 01245 346106 or
info@ageukessex.org.uk

Mind
Advice and support related to emotional well-being
0300 123 3393
info@mind.org.uk

Care Quality Commission (CQC)
Provide feedback on your care
03000 616161
www.cqc.org.uk

As with any face-to-face contact, there can be risks of Covid-19 infection. I am fully vaccinated and will wear a face covering, maintain good hand hygiene, and keep an appropriate distance from you during our conversation. I will also test myself for Covid-19 before visiting you. If you would prefer not to meet in person, the conversation can take place over video call.

How will the information I provide be kept secure and confidential?

After our conversation, I will listen to the recording and write up our discussion for my thesis. The recording will then be deleted. I will include short, anonymised quotes from our conversation in my thesis. Any information that might identify you will be removed or changed when I write up our discussion. The research data will be stored securely using University of East London electronic file storage systems and only the research team will have access to the data. Any data I share with examiners and my research supervisors will be anonymised, so that you cannot be identified.

If I am worried about your safety, or someone else's safety, I may need to share information with other people to keep you safe, such as your care provider. This would be discussed in detail with you.

Data Protection

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal data, please see www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection

What will happen to the results of the research?

The research will be written up as a thesis and submitted to the University of East London for assessment. The thesis will be publicly available on the University's online Repository. The findings may be shared through journal articles, conference presentations, talks, magazine articles, blogs etc. In all material produced, your identity will remain anonymous and it will not be possible to identify you personally. Identifiable information will be removed or replaced when the thesis is written up. You will be asked to choose a different name, which will be used in the thesis to refer to you, instead of your real name. If you would like to, you can receive a summary of the research findings once the research has been completed.

Anonymised research data will be securely stored by Dr Maria Castro Romero or Dr Trishna Patel (the research supervisory team) for a maximum of 3 years, after which all data will be deleted.

Who has reviewed the research?
My research has been approved by the UEL School of Psychology Research Ethics Committee and follows the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Bethany Manning
u2075212@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors, Dr Maria Castro Romero or Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email: m.castro@uel.ac.uk / t.patel@uel.ac.uk

or

Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email: t.patel@uel.ac.uk

What happens next?
If you are interested in taking part in the research, please let your care provider know. We can then arrange to meet in person, or speak over the phone, and I can answer any questions you have.

If you agree to take part, you will be asked to sign a consent form. We can arrange our conversation together for a date and time which is convenient for you.

Thank you for taking the time to read this information sheet.

APPENDIX F: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Care in my own home: Accounts of receiving domiciliary care for the first time
Contact person: Bethany Manning
Email: u2075212@uel.ac.uk

	Please initial
I confirm that I have read the participant information sheet dated 21/07/2022 (version 2) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using an audio-recording device or Microsoft Teams.	
I understand that my personal information and data, including audio/video recordings from the research, will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview and group level data may be used in material such as conference presentations,	

reports, articles in academic journals etc. resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant's Name (BLOCK CAPITALS)

………

Participant's Signature

………

Researcher's Name (BLOCK CAPITALS)

………

Researcher's Signature

………

Date

………

APPENDIX G: Demographics & Background Information Sheet

Care in my own home: Accounts of receiving domiciliary care for the first time

Demographics & Background Information

AGE……

GENDER………

ETHNICITY……

DURATION OF CARE………………………………………………………………………………………………

REASON FOR NEEDING CARE……………………………………………………………………………………

……

CARE INFORMATION………………………………………………………………………………………………

LIVING SITUATION…………………………………………………………………………………………………

ANY OTHER INFO……………………………………………………………………………………………………

……

PSEUDONYM………

APPENDIX H: Interview Schedule

Opening Discussion

- Introductions
- General ice-breaker discussion to build rapport
- **Provide participant information sheet**
- Revisit:
    - Purpose of interview
    - Consent (including consent for audio-recording)
    - Confidentiality and limits to confidentiality
    - Right to withdraw
- Give opportunity to ask any questions
- **Sign consent form**
- Collect demographic and background information (age, gender, ethnicity, living situation etc.)
- Agree upon how long the participant wishes to speak
- Introduce conversational style of interview

******START RECORDING******

Interview

Opening Questions:

When did you start having carers visit your home?
How often do your carers visit?
What do the carers support you with?

"Can you tell me about the first time carers visited your home?" (Or what is the earliest memory you have?)

Prompts:

- How did it come about? /Whose decision was it for you to have carers?
- What were you expecting?
- Did you have any particular fears or hopes?
- What was it like?
- What support did you need?
- What words come to mind when you think about the experience?

"How did you feel about that?"

Prompts:

- What was it like to have someone in your home environment?
- What was it like for you to accept help from someone else?
- What things have been helpful/valuable/positive?
- What things have been challenging?
- Has anything been different to what you expected?
- Is having care something you expected at this point in your life?

“What did it mean to you to need carers at home?” For example, what did it mean to you personally, in terms of your identity, the way you think about yourself etc.

Prompts:

- N.B. Probe into intersectional identities – e.g., What did it mean to you need carers at home as a (woman/man/person of X culture etc.).
- What have you learned about yourself since having care?
- Have you come to realise anything or re-evaluate anything about your life since having care?

“How is your life different since having care at home?”

Prompts:

- Did having care change any of your roles or responsibilities at home?
- Has having care changed any of your relationships in any way? (E.g., with partner, children etc.)
- What have you gained by having care at home? What have you lost?
- Have you noticed any changes in yourself? What have other people noticed/said?
- What would you say to people who are considering having care at home?

******STOP RECORDING******

Ending Discussion

- Reflections on the process (e.g., “How did you find talking today?”, “Is there anything that you have spoken about today that you would prefer not to be included in the write up?”)
- Revisit consent
- Agree pseudonym
- Thank participant for their time
- Give participant the opportunity to ask any questions
- Agree follow-up arrangements (e.g., when the participant can next expect to hear from the researcher)
- **Provide debrief sheet**

APPENDIX I: Debrief Sheet

PARTICIPANT DEBRIEF SHEET

Care in my own home: Accounts of receiving domiciliary care for the first time

Thank you for participating in my research study and sharing your experience of receiving care at home for the first time. This document offers information that may be relevant now you have taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

What will happen to the results of the research?

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on the University of East London's online Repository. Findings will be disseminated to a range of audiences (e.g., academics, health professionals, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs etc. In all material produced, your identity will remain anonymous and it will not be possible to identify you personally. Personally identifying information will be removed or replaced when the thesis is written up. For example, your real name will be replaced with a different name chosen by you.

If you would like to receive a summary of the research findings once the study has finished, please provide your contact details.

Anonymised research data will be securely stored by Dr Maria Castro Romero or Dr Trishna Patel (the research supervisory team) for a maximum of 3 years, after which all data will be deleted.

What if I have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

Age UK
Support and advice for older people
Free confidential advice line: 0800 678 1602
Age UK Essex: 01245 346106 or info@ageukessex.org.uk

Mind
Advice and support related to emotional well-being
0300 123 3393
info@mind.org.uk

Care Quality Commission (CQC)
Provide feedback on your care via www.cqc.org.uk or 03000 616161

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Bethany Manning
u2075212@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisors, Dr Maria Castro Romero or Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email: m.castro@uel.ac.uk / t.patel@uel.ac.uk
or
Chair of School Research Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email: t.patel@uel.ac.uk

Thank you for taking part in my study.

APPENDIX J: Transcription Conventions

Transcription Key

Adapted from Braun and Clarke (2013)

(.)	Brief pause (<2 seconds)
((pause))	Longer pause (2 seconds or more)
((laughs))	Speaker laughs
((coughs))	Speaker coughs
((Laughter))	Laughter involving multiple speakers
/	Interruption
xxx-	Partially spoken/Unfinished
((in overlap))	Overlapping speech
((inaudible))	Inaudible speech
(xxx)	Word is best guess
xxx	Word spoken with added emphasis
“xxx”	Reported speech
[xxx]	Replacement for potentially identifiable information
[[xxx]]	Additional contextual information
[omission]	Omitted speech
*****	Profanity/potentially offensive language

APPENDIX K: Application for Ethical Approval

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS
(Updated October 2021)

FOR BSc RESEARCH;
MSc/MA RESEARCH;
PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form
(please read carefully)

1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics ▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).

1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites: https://www.myresearchproject.org.uk/Signin.aspx https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/ ▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. ▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details

2.1	**Your name:**	**Bethany Manning**
2.2	**Your supervisor's name:**	**Dr Trishna Patel**
2.3	**Name(s) of additional UEL supervisors:**	**Dr Maria Castro Romero** 3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Professional Doctorate in Clinical Psychology**
2.5	**UEL assignment submission date:**	**22/05/2023** Re-sit date (if applicable)

Section 3 – Project Details

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.

3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	**Care in my own home: Elders' accounts of receiving domiciliary care for the first time**

3.2	**Summary of study background and aims (using lay language):**	**The UK has an ageing population and demand on care services continues to increase (Age UK, 2019). Domiciliary care, also known as homecare, is considered the "front line" of adult social care delivery (Jefferson et al., 2018, p.2) and enables many elders who require support with daily tasks to remain living in their own homes. In March 2020, 814,000 adults in England were being supported by domiciliary care services (National Audit Office, 2021). Research into domiciliary care in the UK has predominantly focused on the quality of care elders receive and the challenges facing carers (e.g., Healthwatch England, 2017; Jarling et al., 2020; Jefferson et al., 2018). Limited research in the UK has explored domiciliary care from the elder's perspective and, to date, little is known about what it means to elders to receive domiciliary care for the very first time. Some research into elders' experiences of moving into residential care exists (e.g., Andersson et al., 2007; O'Neill et al., 2020; Thein et al., 2011), yet there is a lack of research into elder's first accounts of domiciliary care. This research aims to elicit and analyse the narrative accounts of elders receiving domiciliary care for the first time. By hearing the stories elders tell of this transition and change to daily life, it is hoped that we will gain a greater understanding of how best to support elders when receiving domiciliary care for the first time and enhance their experiences of care.**
3.3	**Research question(s):**	1) **What stories do elders tell of receiving domiciliary care for the first time? 2) How does receiving domiciliary care impact on the life story, and what meaning is made of this?**
3.4	**Research design:**	**This research will employ a qualitative design. Six to twelve elders (adults over the age of 65) will be recruited and individually interviewed. Interviews will take place in participants' own homes or via Microsoft Teams. Interviews will be audio-recorded, transcribed, and analysed using**

		qualitative analysis, such as narrative analysis or thematic analysis. The analysis selected will be informed by the number of participants recruited.
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	**Six to twelve elders (adults over the age of 65) will be recruited from a domiciliary care provider. Inclusion criteria: Over age 65, Receiving (or previously received) domiciliary care, Capacity to consent to taking part in a research study, Sufficient level of verbal communication in English to partake in conversation without an interpreter. Exclusion criteria: Cognitive or communication difficulties which would restrict participation in an interview.**
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	**A domiciliary care provider has agreed to support recruitment (see Appendix A). The researcher will provide advertising materials for the care provider to share with their clients (see Appendix B) and will inform the care provider of the inclusion and exclusion criteria. The care provider will be asked to identify potential participants from amongst their clients, have an initial discussion with the client about the research, and ask the client if they would be interested in finding out more. If the client is interested in finding out more or taking part, the care provider will inform the researcher, with the client's consent. An introductory meeting will be arranged, via the care provider, during which the researcher will discuss the study with the potential participant and share the participant information sheet (Appendix C) and consent form (Appendix D). The meeting will include an opportunity for the potential participant to ask any questions they have about what participation would involve.**

3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	**Materials, measures and equipment involved include: Password-protected audio-recording device, Access to Microsoft Office, Microsoft Teams and UEL OneDrive, Password-protected computer, Lockable bag/security box, Study documentation (e.g., advertising materials, participant information sheet, consent form).**	
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	**At the point of consent, personal information (e.g., participants' names and signatures) will be collected using a written or electronic consent form. Data will be collected via 1:1 interviews (in person in participants' own homes or remotely via Microsoft Teams). The interviews will be recorded using a password-protected audio-recording device or Microsoft Teams. Participants will be debriefed following the interview and provided with a debrief sheet (Appendix E).**	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☐	**NO** ☒
	If yes, please detail why it is necessary.	If you selected yes, please provide more information here	
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	Please state the value of vouchers	
3.11	**Data analysis:**	**Interviews will be audio-recorded, transcribed, and analysed using narrative or thematic analysis. The analysis selected will be informed by the number of participants recruited.**	

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.			
4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.	Please detail how data will be anonymised	
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	**Participants will be asked to choose a pseudonym, which will be used in all written documentation, except for the consent form. All identifying information collected during the interview (e.g., names of people or places) will be removed (or altered) during transcription. See Appendix F for research data management plan.**	
4.3	**How will you ensure participant details will be kept confidential?**	**Confidentiality, and the limits to confidentiality, will be discussed with each participant during the introductory meeting and revisited at the time of interview (see Appendix G for interview guide). Participants will be asked to choose a pseudonym, which will be used in all written material (except for the consent form). As outlined below, research data will be stored securely using the researcher's UEL OneDrive. A password-protected audio-recording device will be used to record the interviews, if undertaken in person. Microsoft Teams will be used to audio-record the interview, if undertaken remotely. The Microsoft Teams recordings will be downloaded by the researcher from the Microsoft Stream Library and uploaded to the researcher's secure UEL OneDrive. Local copies will be deleted once the files have been uploaded to OneDrive. Any potentially identifiable information given during the interviews will be removed or altered at the time of transcription. Audio-recordings will be deleted following transcription. The recording device and hard copy consent forms will be transported securely using a locked storage case. Hard copy consent forms will**	

		be scanned and then disposed of as confidential waste. Electronic consent forms (including scans) will be saved as password-protected files and stored in a separate folder to other research data on UEL OneDrive.
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	**Research data will be stored securely using the researcher's UEL OneDrive, which is accessible only to the researcher via the researcher's username and password. The researcher will use their own password-protected laptop to access UEL OneDrive and will access UEL systems using multi-factor authentication. Interviews will be audio-recorded by the researcher using a password-protected audio-recording device, if undertaken in person. The researcher will not disclose the password for this device to any other person. The recording device will be transported in a locked case and stored in a locked storage box. Audio files will be downloaded from the device at the earliest opportunity. The audio files will be temporarily downloaded to the researcher's UEL OneDrive to allow transcription. Once transcription has taken place, these audio files will be deleted. The research supervisor will be provided with a copy of the anonymised interview transcripts (to be stored using their own secure UEL account), to ensure there is a backup of this data. Data sharing with the research supervisor(s) will take place via UEL OneDrive (using OneDrive secure links) or UEL email. Electronic scans of consent forms, which will contain identifiable information (e.g., names), will be stored as password-protected files and saved in a separate folder on UEL OneDrive, accessible only to the researcher. A spreadsheet of participant's contact information will also be stored in this way, in another separate folder. If any interviews take place remotely, the Microsoft Teams recordings will be downloaded from the Microsoft Stream Library and uploaded to the researcher's UEL OneDrive. Local copies will be deleted once the files have been uploaded to OneDrive. Files containing**

		identifiable information (e.g., participant names and contact details) will be accessible only to the researcher, using the researcher's UEL OneDrive.	
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	**Files containing identifiable information (e.g., consent forms) will be accessible only to the researcher. Only anonymised data will be shared with research supervisor(s) and examiners. Data will only be shared with examiners upon request. Only anonymised data will be included in the thesis and any subsequent dissemination activities (publications, presentations etc.). The thesis will be publicly accessible via UEL Research Repository. Anonymised data underpinning the research (e.g., full interview transcripts) will not be deposited on the UEL Research Repository.**	
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	**Electronic copies of consent forms will be retained by the researcher until the thesis has been examined and passed and will then be deleted. Research data stored on the researcher's UEL OneDrive will be deleted once the thesis has been successfully examined and passed. The thesis will be stored on UEL Research Repository. Anonymised interview transcripts will be stored by the research supervisor(s) on UEL OneDrive for future dissemination purposes and retained for a maximum of 3 years, after which time all research data will be deleted.**	
4.7	**What is the long-term retention plan for this data?**	**The thesis will be stored on UEL Research Repository. The research supervisor(s) will retain anonymised research data (e.g., anonymised transcripts) for dissemination purposes for a maximum of 3 years following thesis submission. This data will be stored on the research supervisor's own secure UEL OneDrive account and will be deleted once this 3-year period has elapsed.**	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	**See Appendix H for risk assessment form. Potential risks to participants include finding the interview upsetting and Covid-19 infection. During the interview, participants may choose to talk about things they have found difficult about needing care, which some participants may find upsetting. The risk of this will be minimised by offering participants a break or to discontinue with the interview if they show signs of feeling upset. Participants will be aware that they can stop the interview at any time, without providing a reason and without impacting the care they continue to receive from the care provider. The researcher will inform the care provider if a participant finds the interview upsetting and signposting to support services is provided in the participant information sheet (Appendix C) and debrief sheet (Appendix E). The risk of Covid-19 infection will be minimised by the researcher undertaking lateral flow testing on the day of the interview and the interview will only proceed if the researcher tests negative. The**	

		researcher will wear a face covering, maintain good hand hygiene, and request windows are open to provide ventilation during the interview. Remote interviews will be conducted where appropriate and participants will be given the option to be interviewed remotely via video call. The researcher has been fully vaccinated.	
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	**See Appendix H. Potential risks to the researcher include environmental risks associated with visiting participants' homes, Covid-19 infection, and risks associated with lone working. Environmental risks associated with visiting participants' homes will be minimised by thorough discussion with the care provider about the risks related to each participant's home set-up prior to visiting. The care provider will know each participant and their home set-up well. If necessary, a remote interview will be offered. The risk of Covid-19 infection to the researcher will be minimised by the researcher wearing a face covering during the interview, maintaining good hand hygiene, and requesting windows are open to provide ventilation during the interview. Remote interviews will be conducted where appropriate. If a participant tests positive for Covid-19, or displays associated symptoms, the interview will be rescheduled or will take place remotely. The researcher has been fully vaccinated. Depending on the level of risk associated with Covid-19 at the time of interviewing, the researcher may also request that participants wear a face covering and perform a lateral flow test prior to the interview. Risks associated with lone working will be minimised by the researcher informing the DoS and care provider of dates and times of interviews. The care provider will also be aware of the location of the interviews. The care provider has a check-in/check-out system, which the researcher will utilise. The researcher will also contact the DoS**	

		upon leaving each interview. The researcher will discuss each potential participant with the care provider prior to visiting and it has been agreed that the researcher can be accompanied to an interview, if this appears necessary or if the participant would prefer this.		
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:**	**YES** ☒ **See Appendix H**		
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	**Interviews will take place in participants' own homes or remotely using Microsoft Teams. Participants' homes will be in the [Town/City name] area of Essex, where the care provider who has agreed to support recruitment is based.**		
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒	
	If yes, where?	Please state the country and other relevant details		
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics	**YES** ☐		

	survey), regardless of the location of the researcher or the participants.	
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). ▪ For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor). ▪ Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.	

Section 6 – Disclosure and Barring Service (DBS) Clearance

6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☒	**NO** ☐
	* You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended		

	participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☒	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☒	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	**001666993759 (Subscribed to DBS Update Service)**	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** ▪ If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian). ▪ For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.		

Section 7 – Other Permissions

7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☒	**NO** ☐
	If yes, please provide their details.	**[Domiciliary care provider details] – Omitted from this version for confidentiality purposes**	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you	**YES** ☒ **See Appendix A**	

	are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	
7.2	**Additional guidance:** ▪ Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation' or with the title of the organisation. This organisational consent form must be signed before the research can commence. ▪ If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.	

Section 8 – Declarations

8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	**Bethany Manning**
8.3	**Student's number:**	**U2075212**
8.4	**Date:**	**30/05/2022**

Supervisor's declaration of support is given upon their electronic submission of the application

N.B. Appendices have been omitted.

APPENDIX L: Ethical Approval Letter

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in orange

Details

Reviewer:	**Jeremy Lemoine**
Supervisor:	**Trishna Patel**
Student:	**Bethany Manning**
Course:	**Prof Doc Clinical Psychology**
Title of proposed study:	**Care in my own home: Elders' accounts of receiving domiciliary care for the first time**

Checklist

(Optional)

	YES	**NO**	**N/A**
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐

Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options	
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences.

REQUIRED BEFORE THE RESEARCH COMMENCES	Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	APPROVED

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**Dr Jérémy Lemoine**
Date:	**16/06/2022**
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee	
RESEARCHER PLEASE NOTE For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place. For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.	

Confirmation of minor amendments (Student to complete)	
I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data	
Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date
Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required	

APPENDIX M: Amendments to Application for Ethical Approval

University of East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request	
1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒

A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Bethany Manning**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Care in my own home: Elders' accounts of receiving domiciliary care for the first time**
Name of supervisor:	**Dr Trishna Patel**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Use of a video to summarise the information presented in the participant information sheet.	The participant information sheet contains a lot of detailed information. Some potential participants may find it difficult to read and understand a lot of written information and may find the information more accessible and easier to understand if presented in video format. Participants will be given the option to watch the video, in addition to receiving the participant information sheet to keep.
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Bethany Manning**

Date:	**01/07/2022**

Reviewer's decision		
Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**01/07/2022**	

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Bethany Manning**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Care in my own home: Elders' accounts of receiving domiciliary care for the first time**
Name of supervisor:	**Dr Trishna Patel**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Change to research questions	The research questions were amended following a research supervision discussion, in which the researcher and supervisor discussed how best to meet the research aims and address the gap in the literature, with the available supervisory support.
Change to proposed method of analysis	The changes to the research questions indicate that thematic analysis, rather than narrative analysis, would be the most appropriate method of analysing the interview data.
Amendments to the participant information sheet, debrief sheet, advertising poster and DMP to reflect the above	The study materials were amended to reflect the changes in research questions and method of analysis. The previous participant information sheet, debrief sheet, advertising poster and DMP made reference to “stories” or “narratives”, which is no longer relevant now that the research questions and method of analysis have changed.
Addition of questions to the interview schedule in response to change in proposed method of analysis	In response to the change in the research questions, three more interview questions (each with prompts) were added to the interview schedule.

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student’s signature

Student: (Typed name to act as signature)	**Bethany Manning**
Date:	**21/07/2022**

Reviewer's decision		
Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**25/07/2022**	

APPENDIX N: Data Management Plan

UEL Data Management Plan

Completed plans must be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Bethany Manning
PI/Researcher ID (e.g., ORCiD)	https://orcid.org/0000-0002-6451-8736
PI/Researcher email	U2075212@uel.ac.uk
Research Title	Care in my own home: Elders' accounts of receiving domiciliary care for the first time
Project ID	N/A
Research start date and duration	January 2022 – September 2023

Research Description	Domiciliary care services provide support to enable many older people to remain living in their own homes, yet having carers visit one's home can be a significant change to daily life. The proposed study aims to elicit and analyse the accounts of elders (age 65+) receiving domiciliary care for the first time. Individual interviews will be conducted with six to twelve elders. Interviews will be audio-recorded, transcribed, and analysed using thematic analysis. It is hoped that the findings will increase our understanding of how to support elders who require care and enhance their care experiences.
Funder	N/A – Part of Professional Doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	17.01.2022
Date of last update (of DMP)	18.04.2022 - this version updated to reflect changes in title and supervisor 27.05.2022 - this version updated to reflect changes in number of participants and proposed methods of analysis 29.07.2022 – this version updated to reflect changes in method of analysis 12.05.2023 – this version updated to reflect change in Director of Studies
Related Policies	Research Data Management Policy UEL Data Protection Policy UEL Code of Practice for Research UEL Code of Practice for Research Ethics
Does this research follow on from previous research? If so, provide details	No
Data Collection	

What data will you collect or create?	Demographic data for up to 12 participants (age, gender, ethnicity) will be collected to provide context to the interviews. This data will be stored in a single Excel spreadsheet (.xlsx), which will be password-protected and saved on the researcher's UEL OneDrive. Approximate file size is 10KB. Personal data, such as participants' names and signatures, will be collected on consent forms. Consent forms will be scanned and saved as individual pdf files (one each per participant). The hard copies will then be shredded. The consent forms will be saved as individual password-protected files and stored in a separate folder to other research data on UEL OneDrive. Approximate file size is 200KB. Personal data will also be collected prior to interviews, as contact details for participants will be required in order for participants to be interviewed in their own homes (e.g., telephone number, home address). This data will be collected from participants by care provider staff and communicated to the researcher via their UEL email address, or by telephone, and stored in a single password-protected Excel spreadsheet (.xlsx). Approximate file size is 20KB. Up to 12 audio-recordings of interviews will be created. Interviews will be audio-recorded using a password-protected recording device, saved as audio files (.mp3), and transcribed by the researcher. If remote interviews take place, interviews will be recorded using Microsoft Teams. Participants will be asked to provide a pseudonym. Any identifiable information shared during the interview will be removed or altered at the time of transcription (e.g., names, job title). Each transcript will be saved as an individual Word document (.docx). Audio-recordings will be deleted once transcription has taken place. Approximate file size is 15MB. A reflexive log will be kept by the researcher. This will contain no identifiable participant information and will be stored as a single Word document (.docx). Approximate file size is 20KB. Documents will be stored on the researcher's UEL OneDrive. Data will be saved and organised using folders and subfolders on UEL OneDrive. A consistent procedure for file naming will be followed, including the date, title and version number of each file (e.g., 20220117_Trans1_v1.docx)

How will the data be collected or created?	Data will be collected in-person, or remotely via Microsoft Teams, using individual interviews of approximately 45-90 minutes duration. In-person interviews will be audio-recorded using a password-protected audio recording device. This data will be transferred from the recording device to the researcher's password-protected computer via USB connection at the earliest opportunity (i.e. on the researcher's return from the interview) and stored on the researcher's UEL OneDrive. The device will be stored in a locked security box and transported by the researcher in a lockable case. If Covid-19 restrictions prevent in-person data collection, or participants choose to be interviewed remotely, interviews will take place using Microsoft Teams. Microsoft Teams will be used to record the interviews and auto-transcribe the recordings. If the research is conducted remotely, electronic consent forms will be created (e.g., using Microsoft Forms) and stored in a separate folder on UEL OneDrive. Consent information, demographic data and contact details will be collected via consent forms and telephone and email communication between the recruiting care provider and the researcher. Paper consent forms will be transported securely by the researcher using a locked case and will be scanned at the earliest opportunity. Paper consent forms will be stored in a locked security box until they have been scanned and shredded. The reflexive log will be created by the researcher using word processing software.
Documentation and Metadata	
What documentation and metadata will accompany the data?	• Participant information sheets • Relative/carer information sheets • Consent forms • Debrief sheet • Study advertising materials (e.g., flyer/leaflet) • Researcher's reflexive log and field notes • Interview schedule • List of abbreviations/acronyms used in file names The above documents will be produced using word processing software and saved as Word documents (.docx) or pdf files (.pdf).

Ethics and Intellectual Property	
Identify any ethical issues relating to the data and/or data collection and how these will be managed	Ethical approval has been given by the University of East London School of Psychology Research Ethics Committee. The recruiting care provider will be asked to ensure that potential participants have the capacity to consent to taking part in the research, prior to invitation. Potential participants and, if appropriate, their relatives/carers, will be provided with an information sheet about the study and given the opportunity to ask questions, prior to consenting to take part. Participants will be provided with information regarding data management, such as where research data will be stored, how it will be shared, and who will have access to it. Participants will be informed of their right to withdraw from the study at any time, without providing a reason, and without negative consequence. Participants will be informed that they can withdraw their research data within 3 weeks of participation. Participants will be required to sign a consent form if they would like to take part. The consent form will include questions relating to their understanding of the above (e.g., right to withdraw, data management procedures). Consent forms will be stored as password-protected files and stored separately to other research data on UEL OneDrive. Confidentiality, and the limits to confidentiality, will be discussed with each participant and revisited at the time of interview. Participants will be asked to choose a pseudonym, which will be used in all written material (with the exception of the consent form). Any potentially identifiable information given during the interviews will be removed or altered at the time of transcription. Participants will be informed that they may take breaks, pause or stop the interview at any time. Interviews will be audio-recorded using a password-protected audio-recording device or Microsoft Teams. The audio files will be deleted following transcription.

	Participants will be debriefed following participation.
Identify any copyright and Intellectual Property Rights issues and how these will be managed	N/A – No known copyright or Intellectual Property Rights issues. No copyrighted materials are planned to be used.
Storage and Backup	
How will the data be stored and backed up during the research?	Research data will be stored securely using the researcher's UEL OneDrive, which is accessible only to the researcher via the researcher's username and password. The research supervisor will be provided with a copy of the anonymised interview transcripts (to be stored using their own secure UEL OneDrive account), to ensure there is a backup of this data. Electronic scans of consent forms, which will contain identifiable information (e.g., names), will be stored as password-protected files and saved in a separate folder on UEL OneDrive, accessible only to the researcher. The spreadsheet of participant's contact information will also be stored in this way, in another separate folder. If any interviews take place remotely, the Microsoft Teams recordings will be downloaded from the Microsoft Stream Library and uploaded to the researcher's UEL OneDrive. Local copies will be deleted once the files have been uploaded to OneDrive.
How will you manage access and security?	Interviews will be audio-recorded by the researcher using a password-protected audio-recording device or Microsoft Teams. The researcher will not disclose the password for this device to any other person. The recording device will be transported in a locked case and stored in a locked storage box. Audio files will be downloaded from the device at the earliest opportunity. The audio files will be temporarily downloaded to the researcher's UEL OneDrive to allow transcription. Once transcription has taken place, these audio files will be deleted. The researcher will only share anonymised data (e.g., anonymised interview transcripts) with the research supervisor(s) and examiners.

	Data sharing with the research supervisor(s) will take place via UEL OneDrive (using OneDrive secure links) or UEL email. Files containing identifiable information (e.g., participant names and contact details) will be accessible only to the researcher, using the researcher's UEL OneDrive. The researcher will use their own password-protected laptop to access UEL OneDrive and will access UEL systems using multi-factor authentication.
Data Sharing	
How will you share the data?	The thesis will be publicly accessible via UEL Research Repository. Participants will be required to consent to this prior to participation. Anonymised data underpinning the research (e.g., full interview transcripts) will not be deposited on the UEL Research Repository. This is in order to best protect participant confidentiality. Quotations, and any feedback from participants, included in the research thesis (or any subsequent publications, presentations etc.) will be carefully monitored for anonymity and any potentially identifiable information will be removed or altered prior to inclusion.
Are any restrictions on data sharing required?	No one outside of the research team will have access to the research data files. Only anonymised data will be shared with research supervisor(s) and examiners. Only anonymised data will be included in the thesis and any subsequent publications, presentations etc.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	Audio-recordings of interviews will be deleted immediately following transcription. Electronic copies of consent forms will be retained by the researcher until the thesis has been examined and passed and will then be deleted. Research data stored on the researcher's UEL OneDrive will be deleted once the thesis has been successfully examined and passed.

	The thesis will be stored on UEL Research Repository. Anonymised research transcripts will be stored by the research supervisor(s) for future dissemination purposes and retained for a maximum of 3 years, after which time all research data will be deleted.
What is the long-term preservation plan for the data?	The research supervisor(s) will retain anonymised research data (e.g., anonymised transcripts) for dissemination purposes for a maximum of 3 years following thesis submission. This data will be stored on the research supervisor's own secure UEL OneDrive account and will be deleted once this 3-year period has elapsed.
Responsibilities and Resources	
Who will be responsible for data management?	Bethany Manning (Researcher) Dr Tom Kent (Director of Studies/Research Supervisor) & Dr Trishna Patel (Second Research Supervisor) The researcher will collect, store and organise the research data. The research supervisor(s) will be responsible for retaining anonymised data once the researcher has left UEL and deleting this data once the retention period has elapsed.
What resources will you require to deliver your plan?	UEL OneDrive Password-protected audio-recording device (obtained) Lockable bag (obtained) Lockable security box (obtained) Microsoft Office software (e.g., Word, Excel) Microsoft Teams (if required)
Review	
	Please send your plan to researchdata@uel.ac.uk **We will review within 5 working days and request further information or amendments as required before signing**

Date: 12/05/2023	Reviewer name: Joshua Fallon Assistant Librarian RDM

Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (https://repository.uel.ac.uk) or a subject repository. How long should data be retained?

APPENDIX O: List of Initial Codes

List of Initial Codes

- A partnership forms
- Acceptance of change
- Anxious about having care
    - Anxious about personal care
- Anxious about the future
- Appreciating company of carers
- Care following difficult circumstances
- Care is reassuring for family
- Carer enjoys visiting
- Carer is replacing others
- Carers are like family
- Carers are providing a service I am paying for
    - Clear expectations
- Carers are uplifting
    - Carers are motivating
- Carers bring comfort and reassurance
- Carers genuinely want to help
- Carers help in an emergency
- Carers keep me going (carrying on with life)
- Carers need good teaching
- Carers provide emotional support
- Carers represent the outside world
- Carers speak up for me
- Caring is more than a job
- Demonstrating knowledge
- Dependent on care to stay alive
- Disappointing care
    - Carers doing the minimum
- Experienced caring for others
- Feeling like a burden to family
- Feeling useless
- Friendship with carers
- Gender roles
- Getting to know the carers
    - Stranger in your home
- Getting to know you
- Getting used to it
    - Negotiation of roles
- Giving up
- Grateful for support
- Hard to let go and trust others
- Having care is a learning process
- Helping the carers (reciprocal)
- Horror stories about carers are a deterrent
- I don't need help (lack of acceptance)
- Identity change
    - I'm the same person
- Importance of own home
- Irritable with others
- It's about the helpful touches
- It's an intimate relationship
- Lack of expectations
- Lacking control
- Limitations to daily life
    - Frustrated by limitations to daily life
- Maintaining control
- Maintaining independence
- Maintaining sense of humour
- Missing the past
- Need to be respected as a person
- Not my idea to have care
- Others have it worse than me
    - I'm lucky

People skills help

Personalised care makes the difference

Practical and pragmatic reasons (care was needed)

Praise for carers

Pressures on provider

Pride gets in the way

Privacy is important

Process towards care

- Depends on your upbringing

Realisation that help is needed

Realised things about myself

Reliability (I can rely on them)

Remembering past skills

Say yes to care

Security concerns

Significance of financial aspects

Significant life change

Some things aren't a concern

Strictly professional

- Carers have to maintain boundaries

Sympathy for carers

Them (carers) and us

Unexpected part of life

Unknown life expectancy

Valuing conversation

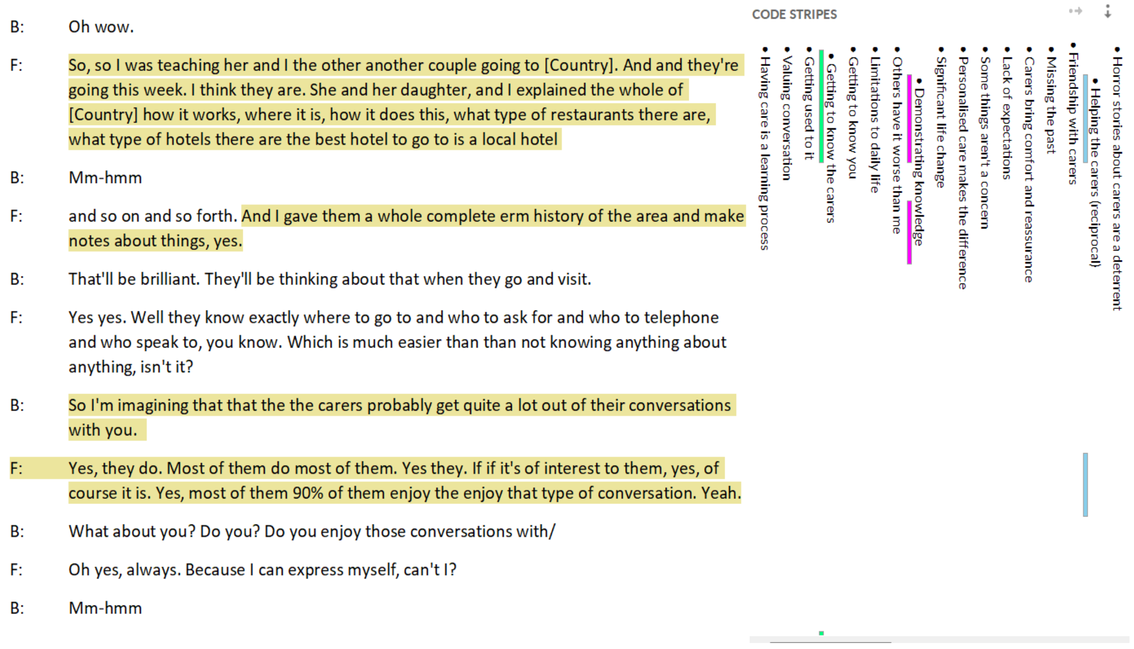
Valuing routine

Wanting more from life

Warmth is an important quality

APPENDIX P: Example Coded Transcripts

Examples:



B: Oh wow.

F: So, so I was teaching her and I the other another couple going to [Country]. And and they're going this week. I think they are. She and her daughter, and I explained the whole of [Country] how it works, where it is, how it does this, what type of restaurants there are, what type of hotels there are the best hotel to go to is a local hotel

B: Mm-hmm

F: and so on and so forth. And I gave them a whole complete erm history of the area and make notes about things, yes.

B: That'll be brilliant. They'll be thinking about that when they go and visit.

F: Yes yes. Well they know exactly where to go to and who to ask for and who to telephone and who speak to, you know. Which is much easier than than not knowing anything about anything, isn't it?

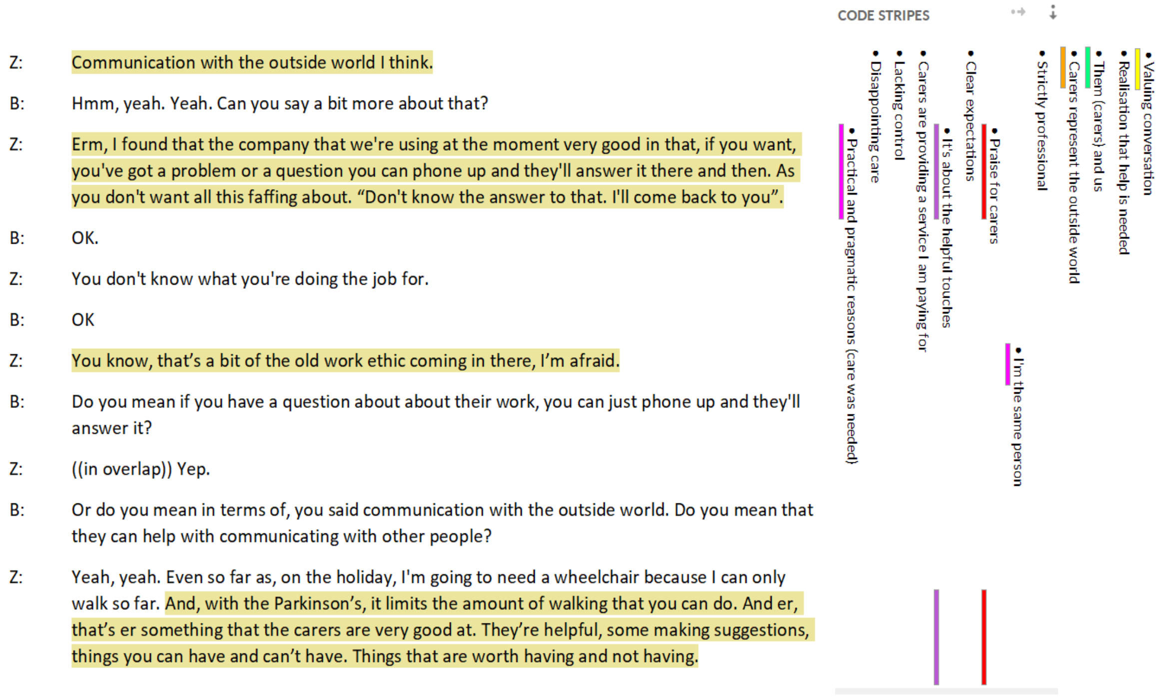
B: So I'm imagining that that the the carers probably get quite a lot out of their conversations with you.

F: Yes, they do. Most of them do most of them. Yes they. If if it's of interest to them, yes, of course it is. Yes, most of them 90% of them enjoy the enjoy that type of conversation. Yeah.

B: What about you? Do you? Do you enjoy those conversations with/

F: Oh yes, always. Because I can express myself, can't I?

B: Mm-hmm



Z: Communication with the outside world I think.

B: Hmm, yeah. Yeah. Can you say a bit more about that?

Z: Erm, I found that the company that we're using at the moment very good in that, if you want, you've got a problem or a question you can phone up and they'll answer it there and then. As you don't want all this faffing about. "Don't know the answer to that. I'll come back to you".

B: OK.

Z: You don't know what you're doing the job for.

B: OK

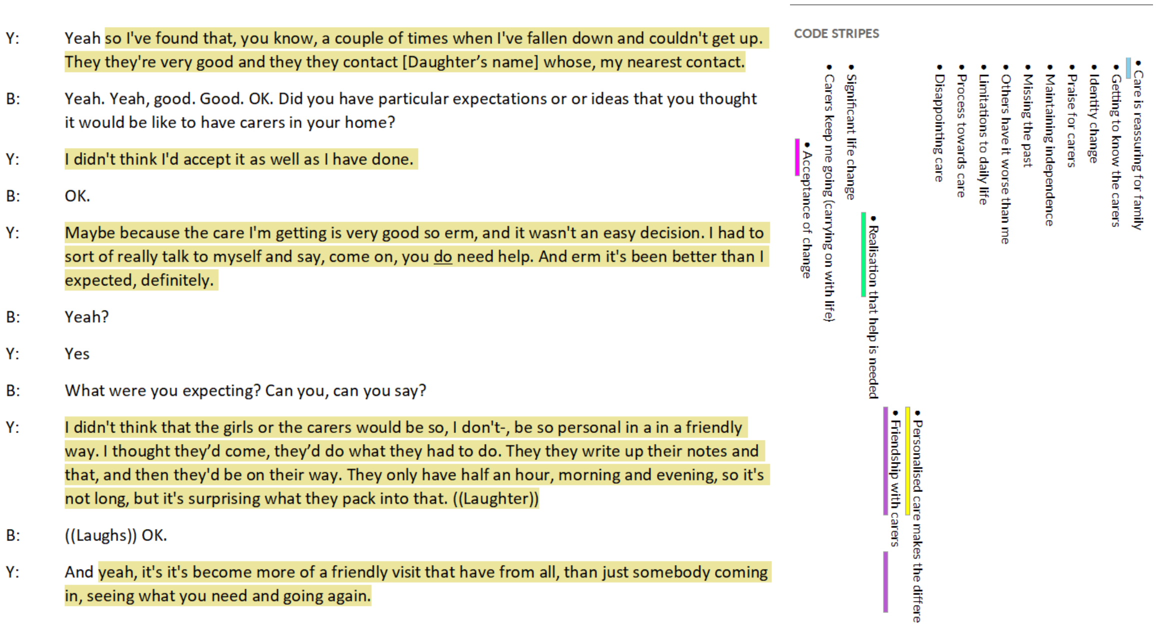
Z: You know, that's a bit of the old work ethic coming in there, I'm afraid.

B: Do you mean if you have a question about about their work, you can just phone up and they'll answer it?

Z: ((in overlap)) Yep.

B: Or do you mean in terms of, you said communication with the outside world. Do you mean that they can help with communicating with other people?

Z: Yeah, yeah. Even so far as, on the holiday, I'm going to need a wheelchair because I can only walk so far. And, with the Parkinson's, it limits the amount of walking that you can do. And er, that's er something that the carers are very good at. They're helpful, some making suggestions, things you can have and can't have. Things that are worth having and not having.



Y: Yeah so I've found that, you know, a couple of times when I've fallen down and couldn't get up. They they're very good and they they contact [Daughter's name] whose, my nearest contact.

B: Yeah. Yeah, good. Good. OK. Did you have particular expectations or or ideas that you thought it would be like to have carers in your home?

Y: I didn't think I'd accept it as well as I have done.

B: OK.

Y: Maybe because the care I'm getting is very good so erm, and it wasn't an easy decision. I had to sort of really talk to myself and say, come on, you do need help. And erm it's been better than I expected, definitely.

B: Yeah?

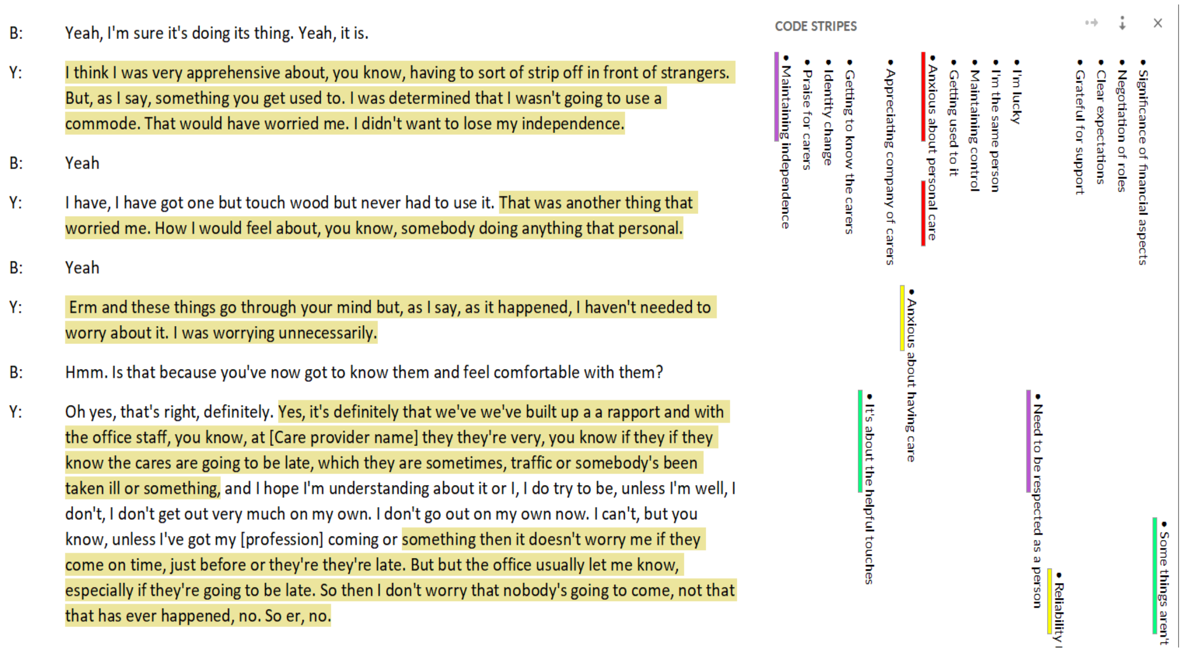
Y: Yes

B: What were you expecting? Can you, can you say?

Y: I didn't think that the girls or the carers would be so, I don't-, be so personal in a in a friendly way. I thought they'd come, they'd do what they had to do. They they write up their notes and that, and then they'd be on their way. They only have half an hour, morning and evening, so it's not long, but it's surprising what they pack into that. ((Laughter))

B: ((Laughs)) OK.

Y: And yeah, it's it's become more of a friendly visit that have from all, than just somebody coming in, seeing what you need and going again.



B: Yeah, I'm sure it's doing its thing. Yeah, it is.

Y: I think I was very apprehensive about, you know, having to sort of strip off in front of strangers. But, as I say, something you get used to. I was determined that I wasn't going to use a commode. That would have worried me. I didn't want to lose my independence.

B: Yeah

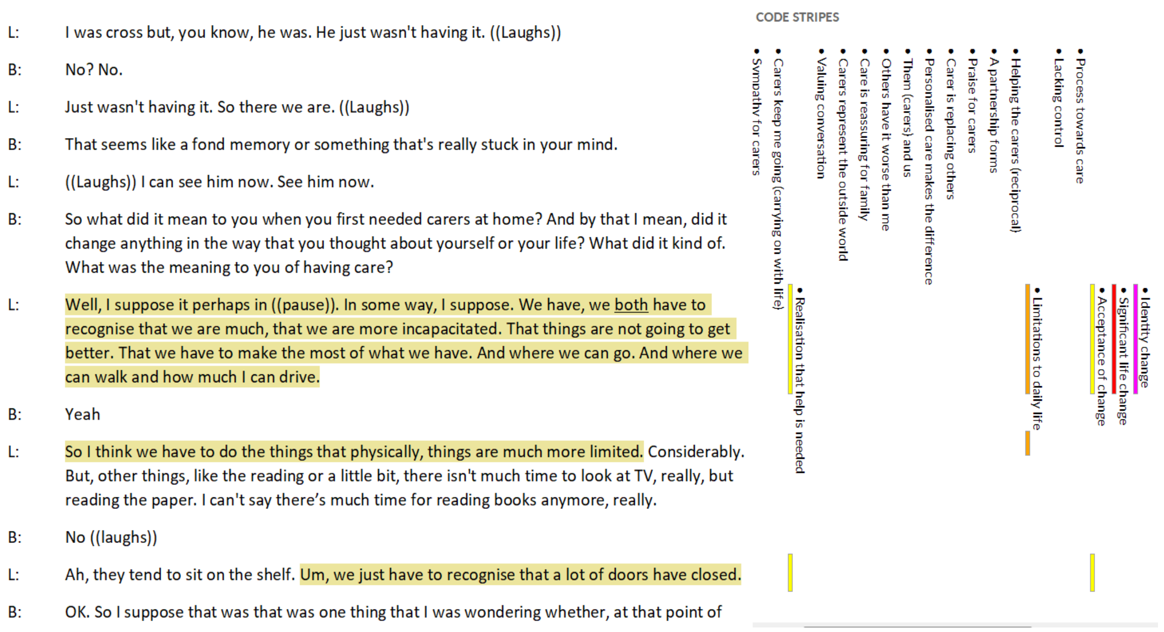
Y: I have, I have got one but touch wood but never had to use it. That was another thing that worried me. How I would feel about, you know, somebody doing anything that personal.

B: Yeah

Y: Erm and these things go through your mind but, as I say, as it happened, I haven't needed to worry about it. I was worrying unnecessarily.

B: Hmm. Is that because you've now got to know them and feel comfortable with them?

Y: Oh yes, that's right, definitely. Yes, it's definitely that we've we've built up a a rapport and with the office staff, you know, at [Care provider name] they they're very, you know if they if they know the cares are going to be late, which they are sometimes, traffic or somebody's been taken ill or something, and I hope I'm understanding about it or I, I do try to be, unless I'm well, I don't, I don't get out very much on my own. I don't go out on my own now. I can't, but you know, unless I've got my [profession] coming or something then it doesn't worry me if they come on time, just before or they're they're late. But but the office usually let me know, especially if they're going to be late. So then I don't worry that nobody's going to come, not that that has ever happened, no. So er, no.



L: I was cross but, you know, he was. He just wasn't having it. ((Laughs))

B: No? No.

L: Just wasn't having it. So there we are. ((Laughs))

B: That seems like a fond memory or something that's really stuck in your mind.

L: ((Laughs)) I can see him now. See him now.

B: So what did it mean to you when you first needed carers at home? And by that I mean, did it change anything in the way that you thought about yourself or your life? What did it kind of. What was the meaning to you of having care?

L: Well, I suppose it perhaps in ((pause)). In some way, I suppose. We have, we both have to recognise that we are much, that we are more incapacitated. That things are not going to get better. That we have to make the most of what we have. And where we can go. And where we can walk and how much I can drive.

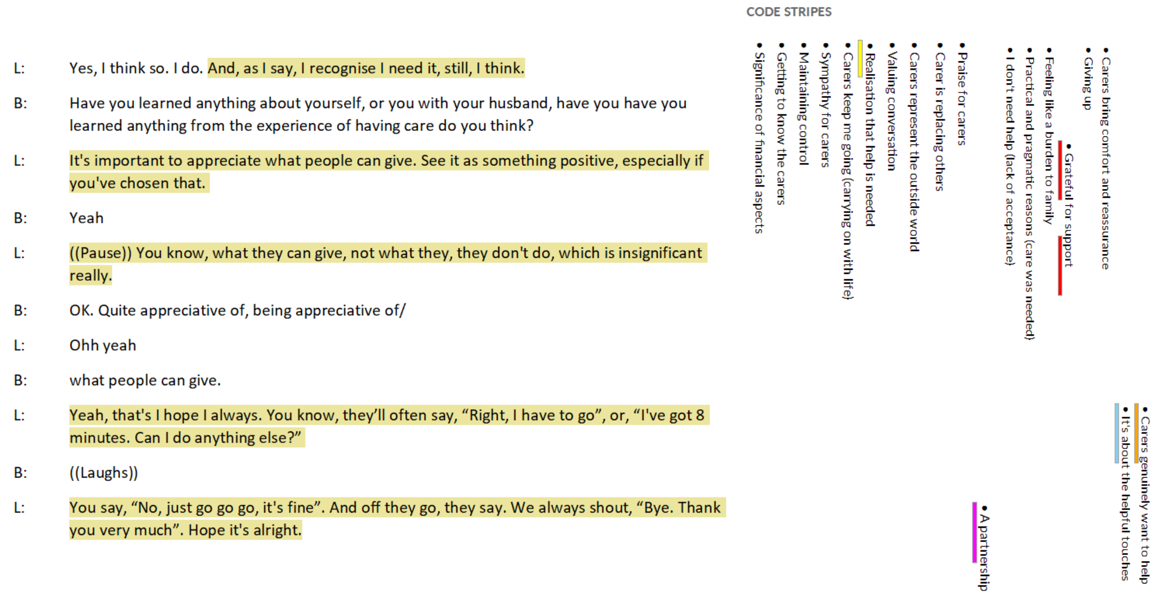
B: Yeah

L: So I think we have to do the things that physically, things are much more limited. Considerably. But, other things, like the reading or a little bit, there isn't much time to look at TV, really, but reading the paper. I can't say there's much time for reading books anymore, really.

B: No ((laughs))

L: Ah, they tend to sit on the shelf. Um, we just have to recognise that a lot of doors have closed.

B: OK. So I suppose that was that was one thing that I was wondering whether, at that point of



L: Yes, I think so. I do. And, as I say, I recognise I need it, still, I think.

B: Have you learned anything about yourself, or you with your husband, have you have you learned anything from the experience of having care do you think?

L: It's important to appreciate what people can give. See it as something positive, especially if you've chosen that.

B: Yeah

L: ((Pause)) You know, what they can give, not what they, they don't do, which is insignificant really.

B: OK. Quite appreciative of, being appreciative of/

L: Ohh yeah

B: what people can give.

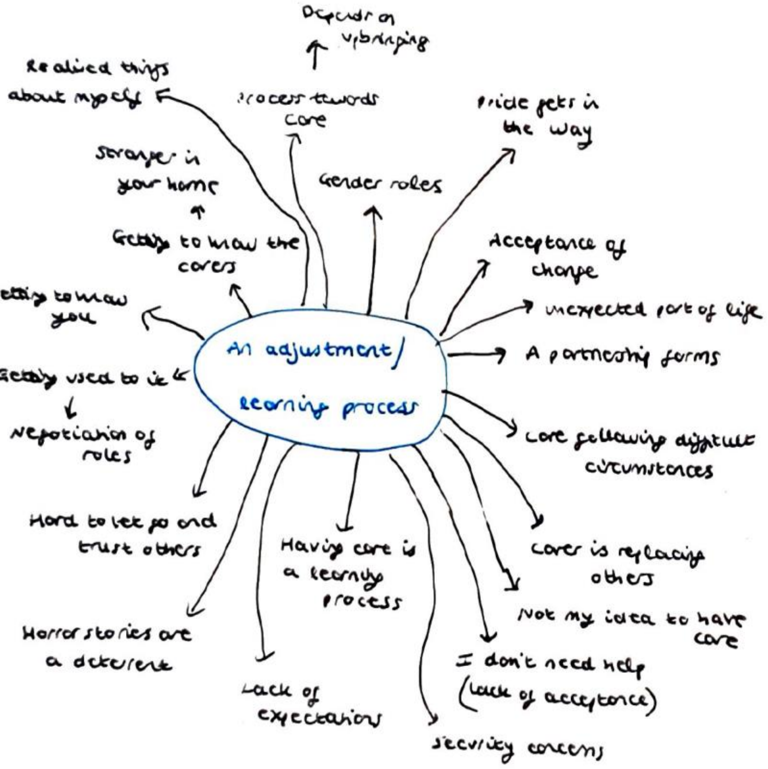
L: Yeah, that's I hope I always. You know, they'll often say, "Right, I have to go", or, "I've got 8 minutes. Can I do anything else?"

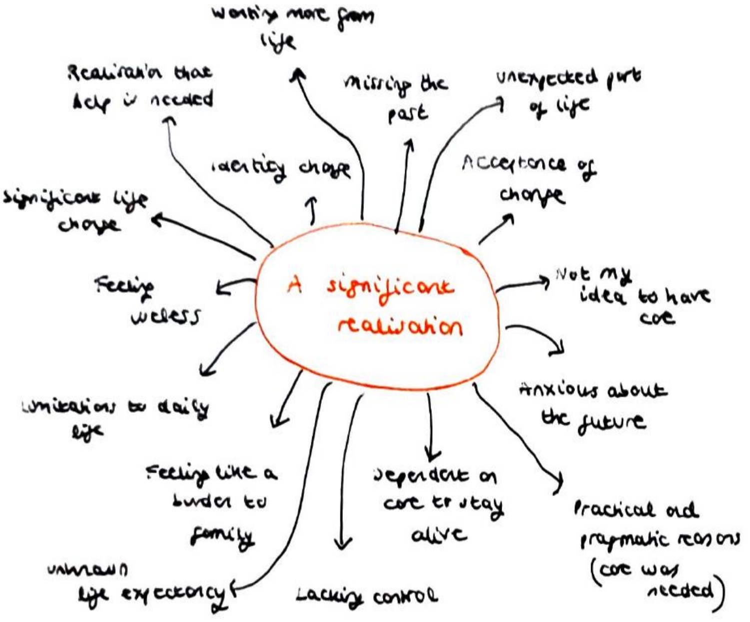
B: ((Laughs))

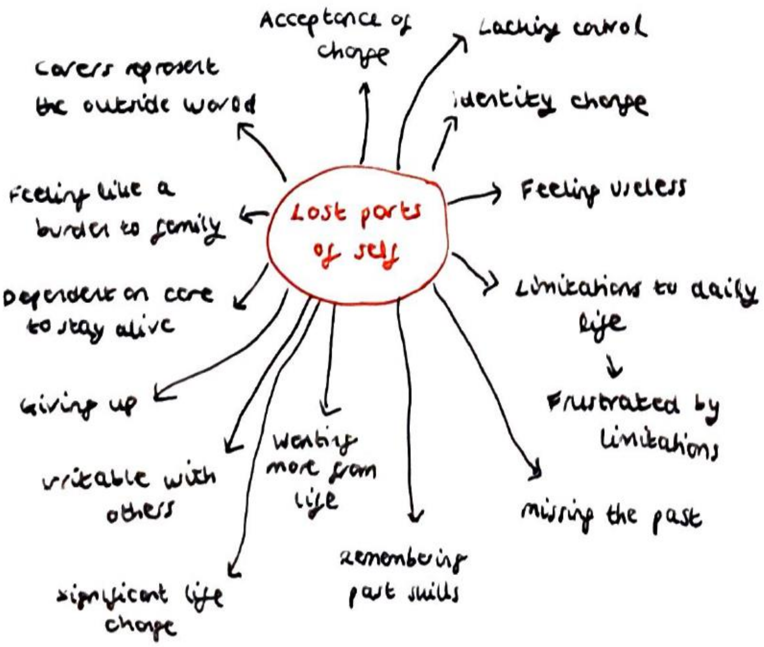
L: You say, "No, just go go go, it's fine". And off they go, they say. We always shout, "Bye. Thank you very much". Hope it's alright.

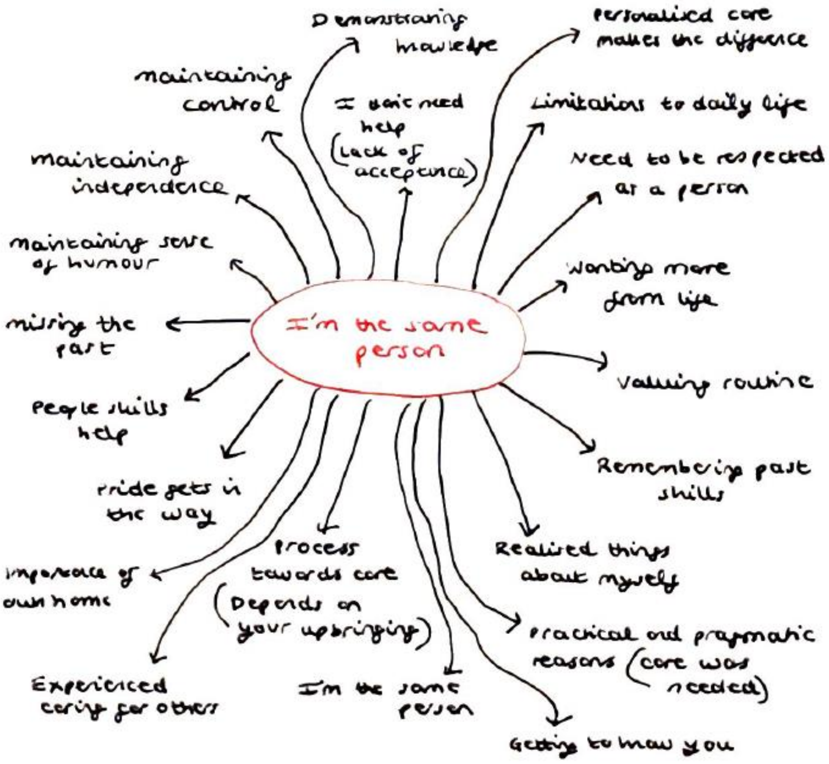
APPENDIX Q: Grouping Codes for Theme Development

Examples:



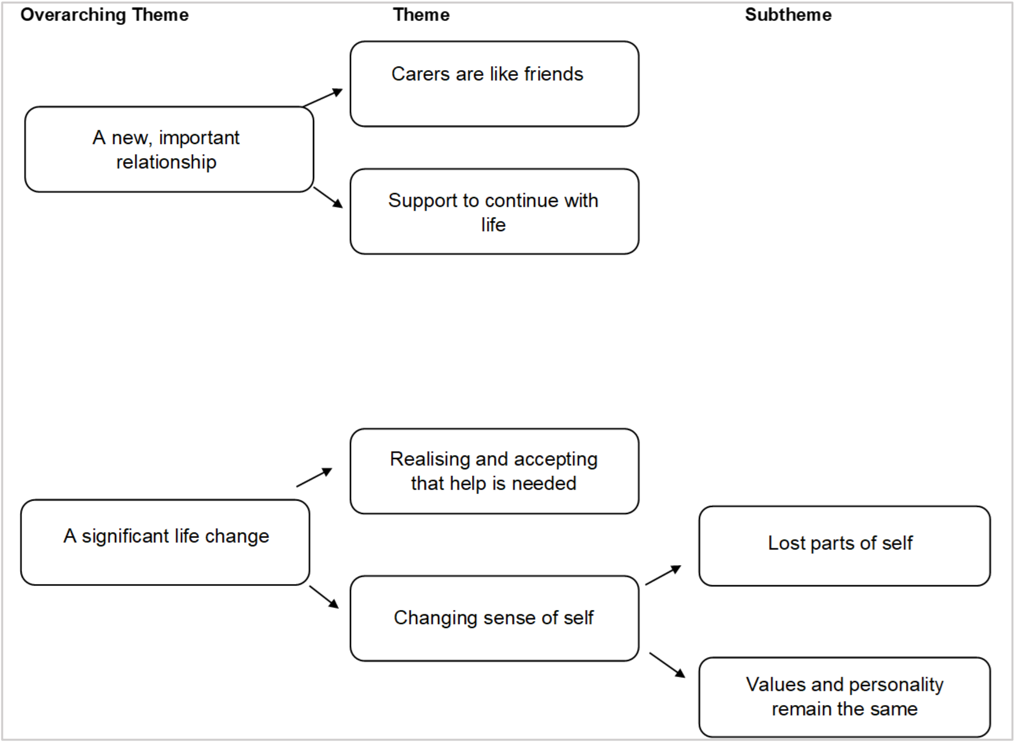


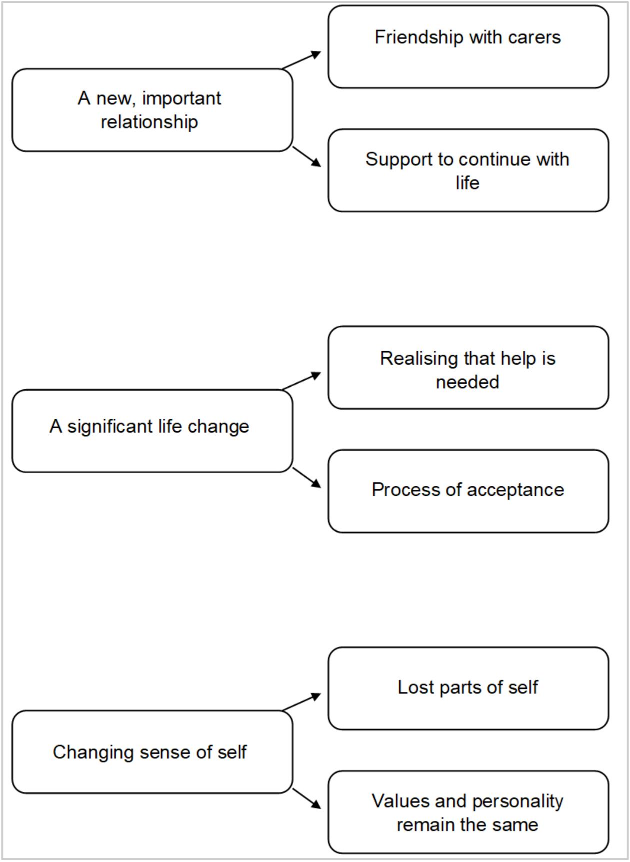

Lost parts of self
Acceptance of change
Lacking control
Carers represent the outside world
Identity change
Feeling like a burden to family
Feeling useless
Dependent on care to stay alive
Limitations to daily life
Frustrated by limitations
Giving up
Wanting more from life
Irritable with others
Missing the past
Remembering past skills
Significant life change


I'm the same person
Demonstrating knowledge
Personalised care makes the difference
Maintaining control
I don't need help (Lack of acceptance)
Limitations to daily life
Maintaining independence
Need to be respected as a person
Maintaining sense of humour
Wanting more from life
Missing the past
Valuing routine
People skills help
Remembering past skills
Pride gets in the way
Realised things about myself
Importance of own home
Process towards care (Depends on your upbringing)
Practical and pragmatic reasons (care was needed)
Experienced caring for others
I'm the same person
Getting to know you

APPENDIX R: Provisional Thematic Maps

Examples:





APPENDIX S: Extracts from Reflexive Journal

Reflections from Pilot Interview

I am pleased with how today went. I was really aware, before today, that the questions were compiled by me, albeit informed by the existing literature and discussions with my supervisor. It felt important to check that the questions were relevant and important to people with personal experience of receiving domiciliary care. After today, I feel much more confident that they are and pleased to have some guidance on additional prompts and questions to include.

The interview was enjoyable! The conversation seemed to flow nicely and it was helpful to have the flexibility to ask follow-up questions depending on what the interviewees had specifically shared. I've already learned things that I wasn't anticipating about the experience of first needing care. I was struck by the sense of vulnerability the pilot interviewees shared in relation to having someone new in their home. I need to remember that the participants may need some time to get to know me and "warm up" before we get stuck into the questions. Many may not have done anything like this before and I will also be a new person coming into their home.

Reflections from Interview

It was a shame that she had difficulty hearing me. I needed to keep repeating things and trying my best to speak louder. She used a magnifying glass to better read the study materials; a small demonstration of being resourceful and adapting to change. Interestingly, she appeared to dislike the more formal part of the interview (reading the PIS and signing the consent form) and was keen to get through this quickly! I got the impression that she was keen to just talk.

At the end of the interview, I felt sad to leave her. She appeared lonely and seemed like she had enjoyed talking to me. I realise I didn't directly ask her about the impact of living alone and whether this made a difference to her experience of care – this could be something to consider for other interviews with participants living on their own.

Reflections from Coding

So many questions are coming up for me whilst coding: Am I doing the data justice? Are the codes I've generated so far analytic or just descriptive/summarising? What if I am missing something? Have I found deeper meaning? It's also hard to know when to stop or how many codes is too many!

It's also really interesting reading through the transcripts again. There's so much there and so much I didn't expect - the strength of friendship, the personal touches, the denial at times that care was needed. There's a lot there which feels very important to capture.

Reflections on Reflexive TA

Learning more about reflexive TA has been an interesting part of this process. Whilst doing the analysis, I have been wondering what other interpretations could be made of the data. What would each participant say? What would a younger adult say? I recognise that there isn't a "correct" interpretation and that interpretation is part of all qualitative research.

Because reflexive TA has been criticised for its subjectivity, I have wondered, at times, whether some people may feel that the results have limited transferability. After thinking some more though, I've realised that interpretation and subjectivity are a part of all the work we do with people. It would be hard to take away that element when doing psychological research or any research involving thoughts, experiences or emotions. People are inherently complex. We work with uncertainty and "not knowing" all the time in clinical work, so it makes sense that subjectivity and interpretation can also be part of psychological research.