An Exploration of the Concept of Well-being In Relation to the Care of Older People

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ABSTRACT

This research explores the concept of well-being as it applies to family carers of older people and the experiences of those carers in the light of a reworked version of that concept. The study is situated within a broader context of the 'care crisis' consisting of an increase in older age care demands alongside a decrease in the resource or care capacity to support demand, resulting in a so-called 'care deficit'. Notions of 'well-being' have become nested within this crisis narrative. During the past five years, particularly in the UK, references to well-being have been explicitly embedded into social care welfare support programmes, and are used to determine and shape how care support services are delivered to carers and those requiring care. However, as well as being ubiquitous, the term is contentious. Its meaning in the care context has yet to be resolved, and in particular, scant critical attention has been paid to the term's significance in the context of care for *older* people. This study responds to this knowledge gap by exploring the meaning and implication of well-being in the context of care of older people.

This qualitative research study provides a full analysis of relevant theory, policy and empirical research addressing well-being and family carers. The central research question is: What is well-being in the context of family care of older people, and why does it matter? The research question is explored through an extended critical engagement with relevant well-being and care theoretical foundations (Nussbaum, 2011; Tronto, 2013) and through a policy analysis of the Social Services and Well-being Act (Wales) 2014. A novel theoretical framework founded upon a social justice perspective and drawing upon critical care ethics and the capability approach is developed. Through critical engagement with the latent meaning of well-being, I argue that the mainstream conception in the context of care is narrow and reductive. Based upon and reflecting ideas about older age and care that mute the value of care as an essential component of all human life and, have the potential in practice to limit and damage family carers' lives and life chances.

In the latter part of the thesis, this framework is applied to primary data gathered through thirty qualitative semi-structured interviews with family carers of older people in Wales. The analysis explores how ‘well-being’ as an enduring ideal defining what it means to live a ‘good life’ interacts with how care in older age is understood. The analysis identifies the key themes of well-being as a multidimensional and relational idea, freedom, choice, vulnerability and dependency. From these findings, I suggest that there is value in theorising an imperfect conception of well-being that acknowledges decline and dependence, particularly in older age care. Furthermore, I suggest a reformulation of well-being in the context of older age care, based upon acknowledging relationality, inequalities and socio-political and cultural contexts. Such a conception, I argue, has the potential to provide a firmer basis on which to articulate and tackle well-being within social care policy and to combat harmful assumptions about the place of care of older people within those systems and the value of caring relationships themselves.

DECLARATIONS

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed .....Maria Cheshire-Allen (candidate)

Date ......16 December 2021

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed Maria Cheshire-Allen (candidate)

Date 16 December 2021

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LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGEMENTS

Parts of the literature review (Chapter 2 – 3) and Findings (Chapter 7) appear as journal articles in:

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1. CHAPTER ONE - INTRODUCTION

1.2 SECTION INTRODUCTION

This chapter presents definitions and terms used, the study's context and background, and the knowledge gaps that the study aims to address. Next, the central research questions, aims, design, and theoretical foundation are highlighted, followed by an outline of the thesis structure provided in the final section.

1.3 DEFINITIONS AND KEY TERMS

The term "family carer" is used throughout the study; however, it is recognised that it is reflective of and shaped by political, cultural, and social factors. In the UK, the term "family carer" is often conflated with other terms such as informal carer, unpaid carer, supporter or caregiver. It refers to anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support (Carers Trust, 2021). In policy and legislation, "Carer" means an adult who provides or intends to provide care for another adult (an "adult needing care"). This definition is used within the Care Act (England) and the Welsh Government's Social Services and Well-being Act (Wales) 2014. This study explores the policy expression of well-being concerning family care and through the Social Services and Well-being Act (Wales) 2014.

This thesis uses the term "family carer" interchangeably with "carer" and "unpaid care". This reflects the preferred term identified in Farina (2017) and in consultation with family carers of people with dementia. The term is used to encompass all informal carers (i.e., family and friends/ neighbours) and, in consultation with carers, was favoured supported most, with "carer" preferred to "caregiver" and "family". And preferred to "informal" in distinguishing family carers from "paid" or "formal" carers. (Farina et al., 2017)

Broadly, someone over 65 in the UK might be considered older. However, it is not easy to apply a strict definition because people can biologically age at different rates. NHS England highlights that rather than biological age, 'frailty' has a more significant impact on someone's likelihood of requiring care and support. In this thesis, and accepting a life-course perspective to ageing (Moen & DePasquale, 2017), an older person is defined as those aged 50 and above, and in line with Welsh Government policy.

Concerning defining the term "well-being", it is noted that despite its widespread interest as a topic of significant academic scrutiny, there is an apparent lack of theory-based formulations of well-being (Seligman, 2011). As Dodge et al. (2012) note, "The question of how well-being should be defined (or spelt) remains largely unresolved." (Dodge, Daly, Huyton, & Sander, 2012, p. 222). In this study, understanding of the concept of "well-being" is broadly informed by well-being theorists McGregor and Pouw (2016), who conceptualise well-being as a multidimensional construct operating within three significant domains of material, subjective and relational. This thesis aims to extend the theorisation of well-being in the context of older age care. Furthermore, in this study and drawing upon a recent review of well-being for carers of people living with dementia (Cunningham, Cunningham, & Roberston, 2018), I rely exclusively on the term "well-being" and exclude the word "quality of life" from discussions. This is because the quality of life is a contested concept and is associated with a different set of factors, and often in the context of older age, these factors are health-related (Bowling & Gabriel, 2004). Therefore, including quality of life could potentially obscure and confuse the focus on the idea of well-being that this study is focused upon. "Quality of life" was excluded from all literature search terms in this study.

1.4 RESEARCH BACKGROUND - 'THE BAD NEWS OF CARE'

This study is focused on the concept of well-being concerning family carers who provide care to older people in the UK. The research is located within a broader context of the so-called 'crisis of care' Hochschild (1995) that refers to the overall narrative of contemporary liberal welfare regimes as defined by Epsing Anderson (1996), experiencing increasing demand for long term older age care. Several key features foreground the need for care, including; an ageing population living with increasing co-morbidities (Vlachantoni, 2019), reduced state-funded formal care provision, changes in family structures, and chronic care workforce shortages (Bertogg & Strauss, 2018). In addition, current figures for the UK suggest that in the next 20 years, the population aged 65 years or over will increase with more individuals reaching 85 years or older who have higher levels of dependency, dementia, and co-morbidity (Kingston, Comas-Herrera, & Jagger, 2018). As a result, long-term care needs are growing and becoming more complex, and there is significant evidence of unmet needs (Bertogg & Strauss, 2018; Pickard, 2015; Vlachantoni, 2019).

Demographic patterns provide a partial picture of the care crisis. Alongside an ageing population and in the UK, since 2010, a programme of significant cuts to welfare spending has been sustained and pursued through so-called austerity-driven reforms. This has resulted in a considerable increase in the numbers of older people (and disabled people) reporting unmet needs (Glendinning, 2017; O'Hara, 2015; Ward, Ray, & Tanner, 2020). Recent figures provided by independent government think tank The Kings Fund show that unmet need for care remains high among older people and in 2018 was twice as high in deprived areas. Furthermore, this report shows that overall demand increased, but long-term care provision fell. Between 2015/16 and 2019/20, 120,000 more people requested social care support, but around 14,000 fewer people received either long- or short-term support (Bottery & Ward, 2021). The 'bad news of care' is promulgated through frequent media reports (Hayes, 2017), and together with the growing demand for care and inconsistencies of coverage connected to the personalisation and marketisation of care (Needham et al., 2018), the care crisis in the UK, appears unabated. In addition, the disproportionate devastating impact on older people of the Covid-19 pandemic has intensified and made these issues ever more critical (Simmonds, 2022).

Situated within this narrative is the family (unpaid) carer of older people. In the UK and elsewhere in Europe, most care provided to older people is unpaid, provided by family or non-kin relations (Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2018). And, recent evidence suggests that most people will care at some point in their lives. Data for the years 1991–2018, from the longitudinal household panel studies, the British Household Panel Survey, and Understanding Society, show that two-thirds of adults had been the carer of someone sick, disabled, or required support in old age. More women are carers than men, and women care earlier in their lives than men, and the mean age for caring in the UK is around 60 years old - more than 1 in 3 (35%) of this age group are carers (Zhang & Bennett, 2019).

Care as a common feature of human experience potentially masks the potentially deleterious effects of caring on individuals. There is unequivocal evidence demonstrating the negative impact that caring can have on an individual's health and well-being; (Pinquart & Sorensen 2003b, 2004; Lai and Leonenko, 2007; Rubin and White-Means, 2009; Keating and Eales, 2017). For those caring for over 50 hours, a week or more, carers report worsening health and well-being after caring (Carers UK, 2015). In Wales, recent survey data reports that people caring for others were more likely than those not to have a limiting long-term illness and be in material deprivation. This relationship was strongest for those who spent more time caring (Government, 2017).

In the UK, concerns regarding inequalities regarding the outcomes of care are muted by a mainstream discourse relating to a crisis of care. This crisis is assumed as borne out of demographic changes resulting in a problematisation of population ageing and older people themselves. Through their associative status as carers of older people, carers as a group are connected to the problem narrative of care of older people, and I suggest that this individualises the responsibilities of care for older people and directs attention away from fundamental social justice questions and the question of responsibility to support carers of older people.

1.5 FAMILY CARER WELL-BEING – AN INCREASING POLICY PRIORITY

The demographic patterns described above contribute to what some scholars call an; 'implicit familism in care', that policymakers welcome to fill the care gap and respond to the 'care crisis' (Kodate & Timonen, 2017). By default, families have been noted as carers, where normative imperatives align with the structural absence of formal options (Sabzwari et al., 2016). Family carers, therefore, are an essential and increasingly relied-upon feature of social care (Cooney & Dykstra, 2011a; Kodate & Timonen, 2017; Saraceno & Keck, 2010), and this reliance as a critical feature of Western European welfare regimes is understood to stem from government policy directives that pursue programmes of de-institutionalisation 'care in the community, and 'ageing in place' (Yeandle, Kröger, & Cass, 2012). As a result, family care is considered central to understanding current social care programmes (Bookman & Kimbrel, 2011; Keating & Eales, 2017b; Moen & DePasquale, 2017), and the significant role occupied by family carers in welfare reform debates have resulted in a raft of legislation and policy aimed at supporting carers (Barczyk & Kredler, 2019; Barnes, 2012; Daly & Lewis, 2000; Yeandle et al., 2012).

As described in the UK, the position of family carers is an increasingly prominent policy issue (Daly, 2002; Daly & Lewis, 2000; Moen & DePasquale, 2017; Naonori, 2017; Ward & Barnes, 2016) and family carers (and those receiving care) are identified as the intended recipients of social care support services. Social care services, often referred to as 'community care' or 'welfare provision,' are designed in the UK to support those unable to support themselves. Since 2014, these services have been organised and delivered around this central concept of well-being. In recent decades well-being in the UK has gained considerable traction as the main organising principle on which services are designed and delivered targeted at unpaid carers. In the UK, during the past five years, family carers have been recognised by the social policy legislation; the Care Act (England) 2014 and Wales (Social Services and Well-being Act (Wales) 2014. Both Acts include the concept of promoting individual and community 'well-being', and in England, the Care Act (2014) provides for a general duty for all Local Authorities to promote individual well-being. In Wales, a well-being policy discourse has been evident for thirty years (Wallace, 2019)

1.6 RESEARCH PURPOSE, QUESTIONS AND AIMS

The purpose of the study is to contribute to a body of evidence that seeks to explore well-being in the context of family care of older people in the UK and the implications of findings on care and well-being theory. Propelling this study is personal motivation and commitment to better understand and contribute to better care and caring conditions. This study is expansive in that it is addressing the broad meaning and implication of well-being within care (for older people), it is *not*, therefore, theorising care concerning 'doing' or 'care work' 'or care as 'being in a relationship' (its' tasks, relationships, emotions, and activities) (Keating & Eales, 2017b). Instead, it seeks to understand how care permeates all aspects of our lives (Fisher & Tronto, 1990) and what an exploration of the concept of well-being concerning family care of older people can tell us about unpaid care of older people more broadly.

The study aims to fill the knowledge gap identified above by critically engaging with current conceptualisations and applications of well-being to explore and develop policy-relevant theorising well-being to older family carers in Wales. The study followed an exploratory qualitative research design, allowing for deep theoretical and empirical insight and acknowledging the complexity and breadth of the subject matter. The study had two main pathways; an analytical concern with how the concept of well-being operates within the context of care of older people and an empirical focus on the properties of well-being that are of significance to carers of older people.

The central research asks;

What is well-being in the context of older age care, and why does it matter? Responding to the research question, three sub-questions and associated aims were developed that rooted the study within the overall purpose.

Table 1 - Research Questions and Aims

Sub Research Question	**Research Aim**

SRQ1. How is well-being understood in the context of family care of older people?	• Critically engage with the scholarly and policy literature relating to well-being and care. • Generate an analytical framework to explore well-being within the context of older age care.
SRQ2. Which attributes or properties of well-being are significant to family carer well-being?	• To gather primary research evidence based on carers' views and experiences of well-being.
SRQ3. What are the implications of this account of well-being on how family care is understood?	• Apply the analytical framework to research findings to explore and understand how family carer well-being outcomes can be understood and supported.

1.7 KEY GAPS IN EXISTING KNOWLEDGE

This study focuses on the idea of well-being within the context of older age care and responds to a significant theoretical and empirical knowledge gap. As a concept, well-being is a widely examined albeit contested concept within research and policy literature (La Placa, McNaught, & Knight, 2013). The idea contains deep complexity, and contemporary well-being theorists have widely recognised the lack of definitional clarity as Thomas, 2009 notes; "intangible, difficult to define and even harder to measure.” (Thomas, 2009). Despite its widespread use, little attention has been paid to the conceptual underpinnings of well-being within adult social care. The relevant academic literature search reveals a surprising lack of clarity and critical engagement with the term. Furthermore, the overt and powerful language of family carer support within government policy of the UK framed by the idea of carer well-being has not easily converted into a broad experience of well-being (as defined by government policy) for the majority of older family carers. Scholarly work shows that care for many increases risk and vulnerability to adverse effects. A large body of empirical work documents negative consequences of care-related economic, social, and health consequences (Bauer and Sousa-Poza, 2015).

The continuing trend and use of the term well-being in UK policy discourse (Bache & Scott, 2018) illustrates that carer well-being is a concept of considerable political interest. Today, well-being has become a somewhat ubiquitous term often conflated with concepts such as quality of life (Michalos, 2013), life satisfaction (Diener, 2012) and happiness (Layard, 2020). It is used as a tool and a value base to determine social care support for carers. Combined with the evidence of carer well-being failures, some carer advocacy and campaigning bodies have questioned the capacity of family carers as a group to respond to and sustain the demands for long-term care needs (Keating, McGregor, & Yeandle, 2021). Furthermore, recent care scholars are calling for a process of 'democratising care' and drawing upon feminist theories of interdependency and social connectedness to argue for a 'caring labour' that contributes to carer well-being and care recipients (Matthew & Bransburg, 2016). Supplementing this call for sustainable long-term care solutions is the idea of a social justice-informed account of carer well-being (Moen & DePasquale, 2017). This study aims to respond to and explore this idea within the context of family care in Wales, UK.

Theories of carer well-being in the context of ageing have, up until recently, been principally concerned with documenting the burden and adverse well-being outcomes that carers can experience as a result of care, and mainly draw upon key theoretical models such as the Pearlin Stress model (Pearlin, Mullan, Semple, & Skaff, 1990) and the Zarit burden scale (Zarit, Reever, & Bach-Peterson, 1980). These are outlined in further detail in the forthcoming theoretical literature review chapter 3.5. These models offer opportunities to describe and detail caring for older people outcomes, and some provide strategies for intervention at policy and practice levels (Daly & Lewis, 2000). However, what is notably absent from these frameworks and, as detailed above, is a political and justice-informed account of well-being in the context of older age care, and political philosophy has primarily left this area of research untended (Engster, 2015).

Moreover, the core ideas of 'care' and 'well-being' have met typically through analysis carried out by political feminist philosophy. However, this work has been mainly connected to care of children and concerning women and gender and has remained theorised in highly ideal terms located at a macro level (Tronto, 2017) and untested against empirical data and policy debates (Yeandle, Yueh-Ching, Fine, Larkin, & Milne, 2017). This study responds to this knowledge gap and builds upon and critically engages with work provided by contemporary care ethicists (Engster, 2015) and care theorists Cunningham and Cunningham (2019) and Keating et al. (2021) to theorise well-being in the context of older age care.

While it has been addressed to some extent and in specific contexts (Barnes, Gahagan, & Ward, 2013; Engster, 2015; Ward & Barnes, 2016; Ward & Gahagan, 2010; Ward, Ray, & Tanner, 2020), the idea of justice and care for *carers* of older people have until recently been relatively absent from the gerontological literature (Moen & DePasquale, 2017). While his work does not focus specifically on older people, political philosopher and contemporary care ethicist Daniel Engster argues for a need in political philosophy to respond to and account for a moral concern for the equality and well-being of others, including high levels of quality care and robust support for caregiving (Engster, 2021).

This study aims to problematise the concept and use of well-being in social care contexts to reveal assumptions and values that replicate and hegemonise understandings of what it means to care and age. An argument rooted in feminist ethics of care scholarship and conceptualised based on work provided by contemporary ethics of care is presented (Barnes, 2012; Engster, 2015; Held, 2006; Kittay, 2013; Kittay, 2011; Ruddick, 2002; Tronto, 1993; Tronto, 2013; Tronto, 2017; Tronto, 2015; Tronto, 1990; Ward & Barnes, 2016). The lack of critical attention to well-being and theoretical framing concerning adult social care can make it difficult to summarise, appraise and apply findings resulting in the potential for lack of evidence-based policy and practice that aims to support positive well-being outcomes for family carers.

To summarise, care ethicists and gerontologists alike have confronted issues relating to the care of older people and from justice informed perspectives. This research represents the first full-length and comprehensive study of the relationship between justice, care theory and policy and drawing upon primary data concerning the particular situation of family carers of older people who may be older people themselves and may also be in need of care.

1.8 RESEARCH APPROACH AND THEORETICAL FOUNDATION

Care and being cared for in older age are inextricably linked to ideas of justice and resource distribution and within broader issues concerning the relationship between the family and the state. Foregrounding these discussions is the question of the responsibility of older age care provision. This study explores these issues beginning from the social reality of family carers. This work was theoretically informed by contemporary care ethics (Tronto, 1993; Sevenhuijsen, 1998; Kittay, 1999; Williams; Ward; Barnes) who, concerning care, calls for a more empirically grounded, policy orientated or 'non-ideal political philosophy, where an analysis is rooted in social facts about the changing demographics and economic circumstances of western democracies and moves beyond 'ideal' theories of just welfare policies (Engster, 2015). To extend this disciplinary work into issues concerning older adult caregiving, care theory is integrated with well-being theory drawing upon work carried out by mainly feminist political philosophers within the literature on the ethics of care, to discern the normative frameworks in which well-being as a concept is understood and applied within welfare provision of older people.

Furthermore, this study responds to the previous so-called crisis of care beginning from a critical perspective. The problems associated with population ageing and caring for older people can be understood as rooted in ageist societal norms and explained within broader neoliberal government arrangements (Carney, 2017; Simmonds, 2022; Ward, Ray, & Tanner, 2020). This account contrasts to the 'crisis narrative' founded upon a dominant idea of a 'dependency care ratio,' which describes the number of working-age people related to the total population. The dependency care ratio is understood to be in part due to several simultaneous events, including; population ageing, increasing numbers of women entering the labour market, persistently low fertility rates, family structural changes, and significant cuts to welfare provision. Rather than promulgating the 'demographic timebomb' narrative, contemporary critical gerontologists argue for a problematisation of the cumulative socio-political effects of population ageing, with recent feminist gerontologists highlighting the ageing demographic profile does not pre-determine problems; that demographic drivers such as migration, fertility, and mortality are all affected by political decisions, and that demography is not destiny. (Carney, 2017).

According to critical gerontologists, the crisis narrative results in problematising ageing and older people themselves and masks deeper complex problems. Alternative accounts of population ageing and the accompanying discourse of crisis of care point to *economic support ratios,* not *dependency ratios*. This shift in emphasis establishes a firm foothold on which to understand societal needs to sustain a population rather than what increasing ageing impacts upon society (Banks, Emmerson, & Tetlow, 2019). The change in focus is intended not to deny or devalue the gravity or chronic state of care in the context of ageing (in the UK and other western nations), but rather to encourage an alternative discourse and an exploration of the socio-political arrangements that impact upon those requiring and providing care. Ultimately to identify features that promote the well-being of everyone involved in caring.

Amid the figures and evidence of unmet and increasing demand for care is the unpaid or family carer, who is critical in responding to and supporting older peoples care needs. This study is focused on carer well-being and the structures and processes that interact with well-being outcomes of the family carer of older people.

1.9 THE COVID-19 PANDEMIC

Amid the coronavirus global health emergency, the aforementioned care crisis has taken on new and critical dimensions. Care has been acknowledged as central to how we respond to and 'build back' after the pandemic (Daly, 2020). Theorists and campaigners have pointed to chronic underfunding and systemic failings that have resulted in the tragic and unnecessary loss of lives, with older people disproportionately represented in mortality rates (Daly, 2020; Littler, Segal, Rottenberg, Hakim, & Chatzidakis, 2020; Simmonds, 2022). This study was carried out during the Covid-19 pandemic in the UK and the fieldwork during the first lockdown during Spring 2020 in Wales. Through their association with the person they care for, family carers are particularly vulnerable to the effects of the disease (Aledeh & Adam, 2020; Giebel et al., 2020; Masterson-Algar, Cheshire-Allen, Hyde, Keating, & Windle, 2021). The closure of many formal services, particularly day centres, and unwillingness to use other services because of the risk of infection led to many people taking on new caring roles. Carers UK estimates that the number of carers more than doubled during the pandemic from 6.5 million to 13.6 million (Kings Fund, 2021).

Moreover, the devastating effects of coronavirus can be traced along socio-economic fault lines in society – hitting the disadvantaged harder and reinforcing existing gaps between those better and worse off (Bambra et al. 2020, JRF 2021). Carers of older people in the pandemic were acknowledged as burdened and vulnerable and identified as heroes in the UK, expressed through the 'clap for carers' movement; however, the unpaid carer supporting older people in communities was invisible. Their recognition was only partial. Arguments for a reformulated account of well-being that incorporates relationality and accounts for carer inequality have been put forward and explored using the ethics of care and capabilities approach to well-being theorisation (Maria & Gideon, 2021).

1.10 THE THESIS STRUCTURE

The following section provides an overview of the thesis structure and the main discussion points from each chapter. A summary of the research process is illustrated below in Fig 1 below.

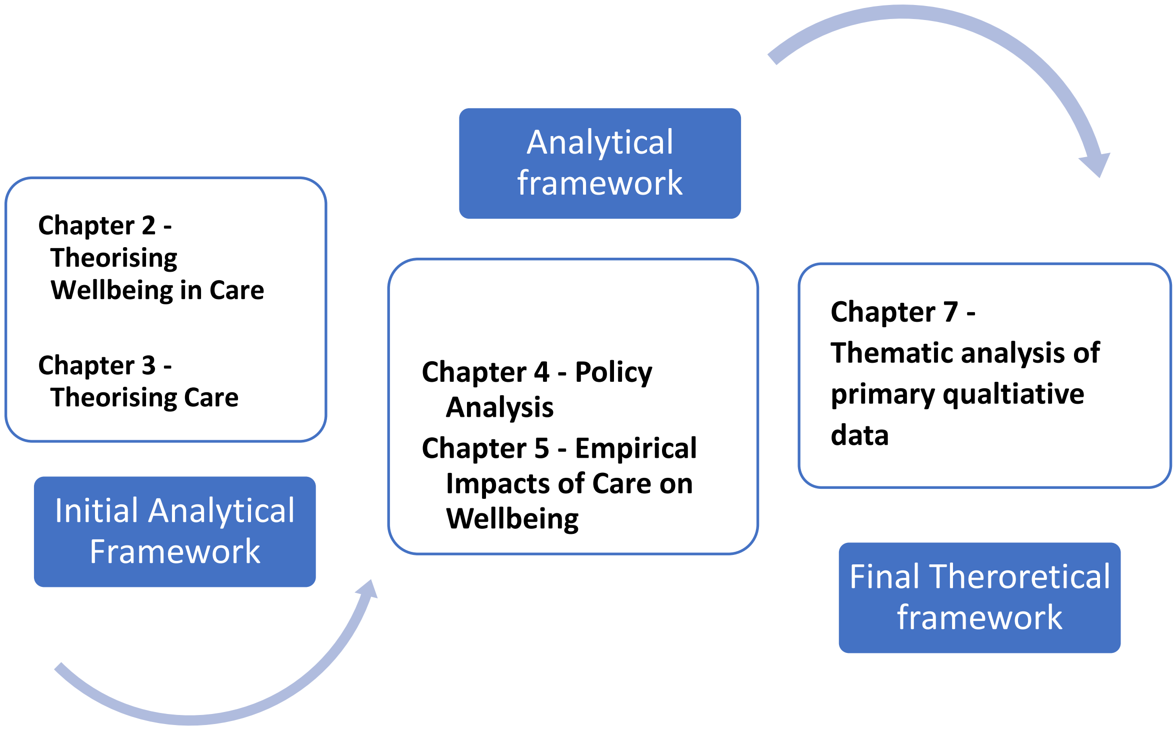

Figure 1 - Summary of research process

Chapter 2 – Theoretical Foundations of Well-being in Relation to Care

A narrative synthesis of the theoretical findings relating to well-being is developed and summarised in Chapter (2.11). In relation to well-being, the literature review highlights two distinct philosophical approaches to well-being are considered; hedonism and eudaimonia. The utility of tracing the roots and values of the approaches to well-being is presented in subsequent sections that bring philosophical discussions of well-being in line with contemporary applications. It is demonstrated how the hedonic approach to well-being characterises well-being policy in the UK today.

Chapter 3 – Theoretical Foundations of Family Care

The care theory exploration culminates in discussing the ethics of care approach to understanding care. I develop an argument establishing this approach as particularly suitable for understanding well-being in the context of older age care, summarised in 3.11.

Chapter 4. An analysis of policy in relation to carers of older people

A policy analysis informed by the theoretical insights provided by the critical review of well-being and care theory is presented in this Chapter. Based upon an examination of the Social Services and Well-being Act (Wales) 2014, the analysis identifies vital findings relating to how family carers are understood and supported in the policy.

Chapter 5. Scoping Review Empirical Impacts of Care on Well-being

The scoping review aimed to identify the consequences of care on carer well-being. The scoping review presents findings based upon the three broad domains relevant in the literature.

Chapter 6 – Methodology and Method

The methodology chapter aims to outline this research's ontological and epistemological foundations. It reiterates the research question and demonstrates the rationale for selecting specific methods. Research reflexivity highlights my professional and personal experience as a carer and volunteer for a local carer's charity. The procedures and research steps taken are detailed. Finally, ethical and procedural issues are outlined and the practical and ethical issues relating to data collection during the initial 'lockdown' in response to the Covid-19 pandemic are explained.

Chapter 7 – Findings and Discussion

This chapter presents the primary data findings based upon thirty semi-structured interviews with carers of older people in Wales. An analysis based upon the results of Chapter 2 –5 is presented. A discussion on the findings is interwoven throughout structured and according to three themes identified through the analysis 1) Well-being as a multidimensional and relational concept 2) Freedom, choice and capacity 3) Dependency and vulnerability. The analysis highlights how structural influences can be understood to exacerbate negative well-being outcomes for family carers.

Chapter 8 – Conclusion

This chapter presents the discussion on findings that reflect on and apply the accumulated knowledge and arguments based on Chapters 2,3, 4 and 5. The chapter reflects on the overall findings and puts forward several policy implications. Finally, it outlines the strengths and limitations of the study and discusses the need for future research.

1.11 THE ROLE AND STRUCTURE OF THE LITERATURE REVIEW

The literature review is prominent in this study. It performs a primary methodological function to generate theoretical insights and inform the development of an analytical framework for understanding well-being in the context of carers of older people. The theoretical insights support formulation of the analytical framework that is applied to the empirical outcomes of impact of care on carer well-being (Chapter Five) and the primary data findings of this research (Chapter Seven).

The lack of clarity of the term well-being in the context of care led to the construction of the first research question; **'How is well-being understood in the context of care of older people?'**. The literature review supports the generation of the analytical framework and contributes to a theorisation of carer well-being in the context of older age care. This is elaborated upon further in Chapter 6 – Method, where I discuss how the study's emphasis on theoretical exploration is aligned with the critical realist methodological approach adopted (6.2).

A critical review was undertaken of the theoretical constructs relating to the key terms relevant to this study: 'well-being' and 'care'. The critical literature review is particularly suitable for theory development (Grant & Booth, 2009). It engages with the theory (rather than mapping the literature) to provide insights for theoretical development. It typically doesn't contain a formal assessment of the quality of studies or systematic steps such as search terms and databases used. In practice, it can be understood as a starting point for subsequent refinement for theoretical development (Burholt et al., 2020).

Chapter Two, begins with the critical review by exploring the literature on well-being relevant to care of older people. The review of the well-being literature culminates in presenting the capabilities approach to well-being as particularly suitable for exploring well-being in the context of older age care.

Chapter Three uses the same critical review method to explore the theory of older age care. It identifies the evolution of care theory as a distinct discipline across multiple fields of enquiry. The feminist ethics of care approach is recognised as particularly salient in responding to the research question.

Chapter Four presents a policy review and analysis of the Social Services and Well-being Act (Wales) 2014. This responds to **Research question 3 – What are the implications of this account on how family carer well-being is understood?**

Finally, responding to **Research question 2 - Which attributes or well-being properties are significant to family carer well-being?** Chapter Five presents findings from a scoping review relating to the empirical consequences of care on well-being. The scoping review aimed to examine the *outcomes* of care on the well-being of family carers. In addition, the scoping study seeks to show the critical empirical features of well-being that are of significance to family carers of older people.

Combined together, the results of the theoretical discussion, policy analysis, empirical impact informed the analytical framework applied to analyse the primary data findings of this study based upon semi-structured interviews with family carers (see Chapter Seven Findings).

The overall structure of the four literature and policy chapters is presented in the diagram below.

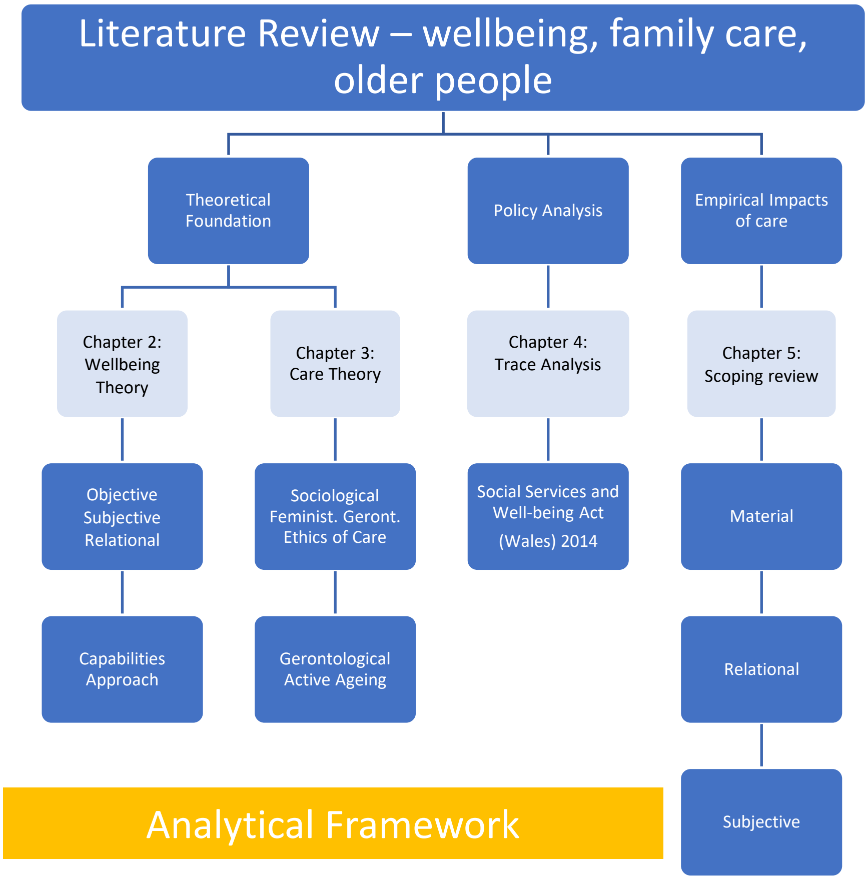

Figure 2 – Literature Review Structure – Theory Policy and Impact

1.12 CHAPTER CONCLUSION

This chapter has provided a rationale for the study and presented the critical research questions, aims, approach, and theoretical foundation. In the next chapter, the literature review findings are presented; these findings provide a basis for an analytical framework for conceptualising well-being about older family care.

2. CHAPTER TWO – THEORETICAL FOUNDATIONS OF WELL-BEING IN RELATION TO CARE

2.1 INTRODUCTION TO CHAPTER

The term ‘well-being’ is a highly contested topic but broadly refers to what it means to lead a good life (Layard, 2015). The term is frequently invoked relating to family carers in policy documents and key government strategies relating to caring for older people. As detailed in the previous Introduction, recognising the complexity of the term and its association with other elusive concepts such as ‘quality of life, compounds the definitional confusion (Morrow and Mayall, 2009). The literature review aims to identify a theoretical framework for understanding well-being in the context of care. The theorisation is used to develop an analytical framework to analyse primary and secondary data evidence of carer well-being.

This first section begins by engaging with the philosophical roots of the concept of well-being and contemporary conceptualisations. This is done to identify contemporary articulations and implications on well-being theorisation relevant to care. This section is structured according to the broad well-being domains identified through contemporary theorists as objective, subjective and relational (McGregor & Pouw, 2016). Specific aspects identified in the literature are discussed throughout.

2.2 WELL-BEING - PHILOSOPHICAL AND CONCEPTUAL FOUNDATIONS

In this section, the philosophical roots of the term well-being are examined. Contemporary Westernised well-being theories can be traced to ancient Greek philosophers; Epicurius (341-270 BC) and Aristotle (384-322 BC). These accounts are understood to form the basis of contemporary articulations embedded in scholarly and policy literature. I will now turn to briefly describe the key philosophical discussions concerning each of the three domains of well-being and connect these ideas to contemporary theorisation and applications to well-being in the context of older age care.

The philosophical roots of well-being are distinguished by the following: 1) The Epicurian approach, characterised by hedonism, broadly defines well-being as a life that is free from pain and maximisation of pleasure. Thus subjective measures such as happiness and desire fulfilment are the defining feature of an Epicurean account of well-being. Moreover, human morality is linked to maximising human happiness (Mulgan, 2013). 2) Aristotle's 'Nicomachean Ethics' begins with the observation that the object of all human striving is eudaimonia (happiness), and the actualisation of happiness is the ultimate articulation of well-being. However, distinguishing from Epircurius, Aristotle attributed to this good a certain kind of virtuous 'activity of the soul' or what is understood as 'eudaimonia' (Kraut, 2015). Eudaimonia is achieved through relations with the social and political world and can be understood as a form of what is now called 'sociality' and an essential aspect of well-being (Dean, 2019). Epicurus' account of well-being is grounded in individuals' subjective experiences of their lives. On the other hand, the Aristotelian account defines well-being as constituted by activity in the social and political world (Austin, 2015a) or, in other words, sociality. Sociality is a crucial feature of this study's discussion, and I connect the foundational ideas of Aristotle's sociality with an ethics of care perspective of relational personhood (Tronto, 2013) to argue that a eudaimonic in origin account of well-being is essential to understanding well-being in the context of older age care.

The path to a good life outlined in the Nicomachean Ethics is a life that exercises distinctly human virtues such as courage, temperance and friendliness – living a good life means being a good human and is related to human's telos or reason for being. It is also profoundly social;

as Austin (2020) explains, a good human can only be achieved in a social setting understood to be ‘sociality’ (op cite). This relates to a type of ‘virtue ethics’ founded by Aristotle. Virtue ethics is understood to have permeated philosophical accounts in Europe up until the early Enlightenment period. However, during the early Enlightenment a new emphasis on the ‘objects of choice and pain avoidance’ aspect of eudaimonia was emphasised, resulting in the valorisation of pleasure or happiness and as the ultimate goal of a ‘good life’ (Eger, 2015). Thus, Aristotle’s ideas of well-being as embodied with virtue was diminished, replaced by a shift towards the emphasis of ‘feelings’ of pleasure and avoidance of feelings of pain characterised by the Epicurian hedonic traditions (Bache & Reardon, 2016), and as shall be discussed, posited individual happiness as the ultimate measure of human well-being.

2.3 OBJECTIVE WELL-BEING

Objective theorisations of well-being can be understood as embodying components of early philosophical discussions. Broadly, it refers to material resources and is typically measured at national levels by gross domestic products and within nations, using household and individual income, employment and housing measures. Material well-being is a crucial element of the current theorisation of well-being and can be traced back to the hedonist tradition of well-being, which gathered traction in the early eighteenth century in the UK, due in part to the highly influential work of British rationalist philosophers and social reformers; Jeremy Bentham (1748-1832) and John Stuart Mill (1806-1873). Together, they developed the moral philosophy 'Utilitarianism', a system of thought understood as foundational contemporary economic and political thought in the UK (Dean, 2019). The concept of utility is central to the hedonistic well-being account. It is used to describe the value of human well-being based on the pleasure or happiness gained from any given action or behaviour (Häyry, 2021). This approach is based on understanding individuals as self-interested autonomous, and rational beings who will seek to maximise their happiness given the right amount of resources and freedoms (Bache & Reardon, 2016).

As a moral philosophy, utilitarianism is based upon Bentham's "fundamental axiom" or the principle of; "It is the greatest happiness of the greatest number that is the measure of right and wrong." (Burns, 2005). John Stuart Mill, a contemporary of Bentham and considered the founder of liberalism[1] - developed Bentham's ideas. Thomas Carlyle (1795 – 1881) famously called Bentham's utilitarianism 'a philosophy fit for swine', unfit for human morality because it recognises no other or higher purpose in human life aside from the mere pursuit of happiness (Hauskeller, 2011). In response, Bentham distinguished between two types of happiness; a feeling or state of pleasure and a state connected to the idea of growth and learning from suffering. Today, these distinctions are used in contemporary 'positive

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[1] Liberalism is a broad moral and political philosophy. Highly influential contemporary liberalist John Rawls developed what is known as the 'contract theory of justice. This describes a society of free citizens holding equal basic rights and cooperating within an egalitarian economic system. Care ethics has provided a strong critique of the central notion of liberal autonomy that Rawl's theory of justice is founded upon.

psychology’ frameworks (Helliwell, Layard, & Sachs, 2012) and are briefly described in the following subsection ‘subjective well-being.’

Despite the significant problems associated with utilitarianism, it has endured as a system of thought. It is broadly accepted as providing the essential foundation for classical economics and political-economic theory in Europe (Adler, 2016; Austin, 2020; Bache & Scott, 2018a; McGregor, 2018). Understood in this way, and about well-being, the idea of utility is used as the guiding principle amongst governments globally, with gross domestic product (GDP) the favoured measure of societal well-being (Austin, 2015). Wealth accumulation and GDP were the primary measures of social progression and were understood broadly as objective well-being measures.

Objective well-being consists of ideas relating to material living standards, resources and access to resources that a person has. In the UK, objective well-being scores are gathered through administrative survey data focused on questions concerning physical health and education and income, including all sources of income from employment, private pensions, investments (Bache & Scott, 2018a). In addition, welfare support programmes were based on a general agreement that the happiness scores of individuals can be improved by supporting objective measures emphasising fiscal growth (McGregor & Pouw, 2016). In the mid-1960s, however, GDP as the final measure of human well-being was challenged to be complemented by accounts that aim to understand individual and social well-being beyond wealth and incomes. A summary of the subjective well-being domain concerning care follows.

2.4 SUBJECTIVE WELL-BEING – THE GREATEST HAPPINESS FOR THE GREATEST NUMBER

The contemporary application of subjective well-being has been traced along two primary waves in the European and North American context (Bache and Reardon, 2013). The first, beginning in the post-war USA, is understood to have been marked by a speech given by Robert Kennedy that challenged the idea of GDP as the sole indicator of social and individual well-being; "GDP measures everything, in short, except that which makes life worthwhile." (Kennedy 1968, cited in Austin, 2020). This speech can be understood as in part a response to increasing evidence and recognition of what is referred to as the 'Easterlin paradox'. Based on work carried out in Richard Easterlin (1978). An American economist, Easterlin showed that despite a steadily growing American economy over the previous decades, the average happiness had remained almost unaltered. Furthermore, Easterlin showed that happiness varies directly with income both among and within nations but over time, happiness does not trend upward as income continues to grow (Easterlin & O'Connor, 2020; Gillett-Swan & Sargeant, 2015; Jenkins, 2018). The Easterlin paradox, was accompanied by evidence of increasing inequalities and wealth accumulation. As a result, the primary measure on which to base societal well-being was questioned, and alternative terms to measure society's growth and development were sought (Layard, 2006; Oishi, Schimmack, & Diener, 2012).

Subjective well-being scores began to be developed at global levels in the 1990s, beginning with the Human Development Report (1990) that provided for one of the first initiatives to develop human well-being as a measure of nation's progress beyond GDP (Joseph & McGregor, 2020; UNDP, 1990) and sparked a renewed emphasis amongst western democracies on well-being as a policy tool to guide and deliver positive outcomes for societies 'beyond GDP' (Jenkins, 2018).

Defining subjective well-being broadly, Diener (1999) argues it is a broad category of phenomena that includes people's emotional responses, domain satisfactions, and goals, and life satisfaction constitutes one of the most frequently adopted proxies (Diener, 2012) and specific instruments that aim to provide individual measures of the overarching judgement of life satisfaction and happiness have been developed (Cummins, Mellor, Stokes, & Lau, 2010;

Diener, 2012; Ryff, 2014; Seligman, 2011). Moreover, subjective well-being is specific to an individual and a time; it can be felt 'in the moment' or be part of a longer-term evaluation of how one's life is going (Gillett-Swan & Sargeant, 2015). Therefore, the contemporary theorisation of subjective well-being can be further sub divided into distinguishing between happiness as a state or as a fluctuating mood. Helliwell et al. (2012) distinguished *affective,* emotional happiness (feelings of happiness), which can be understood as belonging to a hedonistic tradition and *evaluative* happiness (life satisfaction) and feelings of self-worth or the eudaimonic aspects a longer-term evaluation of how life is going (Helliwell et al., 2012).

In summary, hedonic happiness is essentially about the experience of feeling 'good' and is generally seen as comprising two main domains; cognitive - feeling good about one's life, life satisfaction and affective sense good in one's life and positive emotions associated with this (Lomas, Case, W.F., & VanderWeele, 2021). In contrast, the eudaimonic perspective of happiness denotes self-actualisation and ethical practices and improvement (Ryff, 2014).

The above discussion provides a detailed account of well-being theorisation relating to objective and subjective domains. Detailed theoretical constructs are essential to this study's discussion. This is because the basic foundations and assumptions concerning well-being are contained within contemporary articulations, and welfare support programmes are understood to be embedded with ideas of well-being belonging to both hedonic and eudaimonic happiness traditions (McGregor, 2018). I shall now turn to briefly discuss subjective well-being accounts concerning happiness, a specific feature of subjective well-being and apply these theories to understanding well-being and care.

2.5 HAPPINESS

Happiness is a predominant feature of subjective well-being accounts. It is broadly acknowledged as a specific component of subjective well-being and is used within global well-being measures (Layard, 2020). It is evident within personal opinion polls found within government-administered surveys and administrative data sets (Helliwell & Wang, 2012; Layard, 2020; Seligman, 2011; Veenhoven, 1994). As a key component of subjective well-being measures, happiness originates from well-established scholarly work belonging to positive psychology and has been dubbed a ‘new science of happiness’ (Layard, 2006). This work is based upon the central claim that happy people are healthier, more socially engaged and more successful (Kahneman, Diener, & Schwarz, 1999; Layard, 2006; Seligman, 2011). In the UK, notable contemporaries of the happiness as well-being account include economist Lord Layard (2020, 2018, 2011), who has led national ‘happiness’ campaigns and explicitly made claims to public policy as playing a pivotal role in promoting individual happiness; “Happiness should become the goal of public policy” (Layard, 2011, p 147). Although this approach has attracted widespread accord, challenges have been levelled against happiness as well-being accounts.

Grant Duncan (2014) provides a relevant exploration of the idea of self-care within well-being as happiness debates. Duncan refers to a proliferation, particularly in the west of ‘self-help’ or ‘new-age’ literature articulated as mindfulness. Duncan highlights how this ideology assumes that the route to happiness is a matter of choice. Happiness is not merely a product of luck or fortune but is attainable by adopting a certain ethic. Aligning with the broader care discussions above, Duncan notes self-help as; “While very apolitical on the surface, this discourse should be read for its implicit politics of individual choice and responsibility – in effect, an ethical privatisation, an ‘ethopolitics’ or a set of ‘techniques of the self’ (Duncan, 2014).

A further important critique to the well-being as happiness account is provided by Annie Austin (2018, 2020), who discusses how the components of happiness detailed above are exemplified in the current UK government ‘measuring national well-being programme’. Implemented by the then Prime Minister David Cameron, the UK’s Well-Being programme aims to provide a national well-being measurement framework administered through the Office of National Statistics. The framework reflects and incorporates the three domains of well-being highlighted in Chapter Two. (Bache & Scott, 2018a).

Austin (2020) argues that this account of well-being is founded upon the classical utilitarian hedonistic thinking that uses happiness or (hedonistic) individual measures of well-being as the ultimate goal or measure of well-being alongside objective GDP measures (Austin, 2020). Austin identifies discursive assumptions embedded within UK Government policy that show

how well-being is equated with a subjective state and implies that the maximisation of subjective satisfaction is the assumed policy priority. The specific domains mentioned (community participation, housing condition) are valued primarily in terms of their causal contribution towards the primary goal of achieving high levels of subjective satisfaction (Austin, 2015a). Austin asserts that this results in an overemphasis on happiness and a 'hegemony of happiness' evident within the UK well-being policy. This is problematic as it is reductive and results in confinement or a blinkered understanding of well-being (Austin, 2015b; Farina et al., 2017).

Happiness has thus served as a critical term in developing the modern 'social contract' said to underlie the welfare state's systems of rights and duties (Duncan, 2014). In the context of unpaid care and carer well-being, the critique provided by Austin is particularly salient. The monistic use of happiness terms in public policy is problematic as it ignores the pluralistic ways in which other aspects of life such as good health, relationships, and material resources impact well-being. These aspects are merely understood as causal contributors to the ultimate goal of subjective well-being states (Austin, 2015). Subjective well-being measures can be seen to mask particular group inequalities; thus, a focus on individualism obscures structural disadvantage. In relation to carers, there is unequivocal evidence demonstrating the negative impact of caring on an individual's health and well-being; (Pinquart & Sorensen 2003b, 2004; Lai and Leonenko, 2007; Rubin and White-Means, 2009; Keating and Eales, 2017). Secondly, an over-reliance on subjective well-being denies the importance of fulfilling social relationships and in the case of care, and as will be discussed in the next section, connecting to others through a type of relational personhood is the foundation of care ethics, and it is hypothesised that carer well-being depends upon the well-being of others. In this sense, relational well-being is constitutive of well-being, not simply a contributor to it. Furthermore, and relatedly a key criticism in relation to the dominance of subjective well-being scores is that it assigns personal responsibility to individuals for their own happiness and is understood within broader neoliberal welfare regimes (Austin, 2020)

As shall be discussed and presented in Chapter Five there is a predominant focus on outcomes of care on carer well-being theorised and measured mainly through subjective well-being. These theories broadly understand the negative associations that care can have on carers well-being and are based upon individual ‘burden’ measures (Cunningham, Cunningham, & Roberston, 2018). I suggest these are examples of Austin’s ‘Hegemony of happiness’ account of well-being and argue this is significant to this discussion because it overshadows the structural in origin features of care outcomes on carers, and prevents social justice informed questions concerning care.

For the purposes of this study, subjective well-being is defined by McGregor and Pouw (2016), who argue that subjective well-being involves having a goal in mind and making choices to pursue what is regarded as important for personal well-being concerning others (McGregor & Pouw, 2016). This understanding of subjective well-being can be understood as aligned with a capabilities approach to well-being originating in the seminal work of economist and philosopher Amartya Sen (1985, 2001, 2017). In the next and final section of this current discussion on well-being theory, I introduce and detail the capabilities approach (CA) to well-being through the work of Amartya Sen and Martha Nussbaum. I establish the foundations for an argument that asserts that the capabilities approach to well-being provides essential theoretical tools to understand well-being in the context of family care and older people

2.6 RELATIONAL WELL-BEING

A relational or social dimension to well-being can be understood as a bridge or mediator between the subjective and objective accounts of well-being (McGregor, 2018). It responds to subjective well-being measures - happiness theorisations. Fully formulated accounts of relational well-being are provided by Amartya Sen (2001; 2017) and Martha Nussbaum (2003, 2011) in what is termed the 'Capabilities Approach' (CA) and are widely held to be a significant contribution to well-being theory (Deneulin & McGregor, 2010; Devereux & McGregor, 2014; Dodge et al., 2012; Eger, 2015).

Adopting a relational element to accounts of well-being begins from the assumption that to be well, we need supportive connections with others (Keating et al., 2021). Sen articulates social or relational aspects of a person's life - the relationships that people have or don't have, as vital enablers to well-being and their exercise of capabilities (Sen, 2017). It can be understood as referring broadly to the relationships, connections and quality of relationships that carers have in relation to their care. I will briefly outline the CA to well-being and apply these ideas to carers of older people in the next section.

Sen (1985) challenged the utilitarian, hedonic idea of utility satisfaction as the basis of well-being measures. Sen highlights a vital flaw in the hedonic account in 'the adapted preferences' argument (Sen, 1985, 2001, 2017). At its basis, this argument shows that people with similar living conditions are evaluated quite differently and that people in bad conditions frequently are satisfied, conversely privileged people may report dissatisfaction. Sen, therefore, rejects the notion that individual assessments of well being should come from subjective assessments, as people in dire situations can adapt; "The metric of pleasure or desire may sometimes be quite inadequate in reflecting the extent of a person's substantive deprivation." (Sen, 2017, p. 24). In the context of family carers, we can appreciate the significance of this line of argument. The idea that family carers could report adequate subjective well-being scores, but experience negative (as detailed previously) structurally derived inequality is important. It is an idea that is returned to in the policy analysis chapter 4, where measures of well-being are assessed in terms of the issues highlighted here.

Empirical evidence consistently shows that despite extreme forms of human deprivation, poverty and abuse, individuals can report positive well-being measures. Sen's 'adaptive preferences' argument enables a social justice inspired account of well-being. Contemporary CA theorists argue that objective benchmarking of well-being drawing upon empirical evidence is necessary to consider that humans adapt to external (adverse) circumstances (Austin, 2018). Counter arguments and claims have been made to this central feature of the CA to well-being. For instance, Begon (2015) challenges the central precept of the adaptive preferences account, claiming that it undermines individual agency (Begon, 2015). These challenges, however, fail to recognise the critical difficulty of subjective well-being accounts in that they conceive of humans as operating as autonomous, rational individuals. Individualism has been identified as a critical discursive feature of care policy in the UK (Lloyd, 2010; Lloyd et al., 2014; Moffatt, Higgs, Rummery, & Jones, 2012) and can be traced back to the utilitarian account of human well-being outlined in the above section. The problem of individualism inherent within subjective well-being theory relates to assigning responsibility to individuals for their happiness. This ignores the adaptive preferences problem articulated by Sen and what is considered by many to be the fatal flaw of subjective well-being arguments (Austin, 2018).

The CA has provided a clear theoretical framework for international policy on human well-being. In 2009, the highly influential Stiglitz-Sen-Fitoussi Commission published its final report. Key authors of the report, Sen and Joseph Stiglitz, provided for the first time a multidimensional concept of well-being, arguing that measurement of human progress must include metric's capable of measuring people's assessment of their lives which travel further than levels of income and individual happiness scores and that had an objective, subjective and relational measures of well-being (Stiglitz, 2009). The report defined well-being that included eight domains that can be measured using both subjective and objective and relational indicators. This account has gained widespread influence with countries worldwide adopting a multidimensional conceptualisation of well-being that includes three aspects material, subjective and relational (Robeyns, 2006). This broad understanding of well-being comprises the three dimensions is used throughout this study.

A detailed discussion on the capabilities approach to well-being and its application to family care of older people is outlined in the next section. Three central claims are made on which to base the preference for a CA to well-being in the context of care, these are:

- The CA emphasises a relational understanding of well-being
- Challenges individualism and accounts for the socio-political aspects that influence individual capabilities
- Begins from a social justice perspective based upon Amartya Sen's conception of 'substantial freedoms'

2.7 THE CAPABILITIES APPROACH TO WELL-BEING, AND FAMILY CARE

The relational aspect of well-being is conceptualised as a process within a social context generated through relationships with others (Deneulin & McGregor, 2010). This provides the basis for the first claim for a CA inspired theory of well-being in the context of care, emphasising relationality. The CA account of well-being offers a type of social definition to well-being that can be seen to challenge contemporary policy responses to well-being which are individualised and market-led (Austin, 2015). The CA to well-being can be understood as an extension and type of Aristolean account of well-being (Austin, 2020). It conceives human nature as grounded in sociality and thus presupposes a type of relationality (Austin, 2020). Conceiving human nature in this way, I argue, is particularly applicable to care – it creates theoretical space to account for the inevitable need for care (Kittay, 2011) and dependency on care as a universal and essential feature of human life. Furthermore, and importantly for a discussion on well-being in the context of care of older people, the CA; "Builds growth and decline into the trajectory of human life."(Nussbaum, 2011, p. 32)

At its core, the CA advocates that our focus should be on what people can *do* and *be* rather than what they have or how they feel (Sen, 2001). Sen rejects a unidimensional approach to well-being, instead advocating focusing on ends – the capabilities individuals have, rather than means or their resources. In essence, capabilities are the freedoms individuals have, their 'real opportunities' to achieve a desired functioning (Robeyns, 2006). The outcomes of capabilities are *functionings*. In contrast to previous accounts of well-being, Sen and Nussbaum hold that capabilities are central for people and are different in quality, not just in quantity. Therefore, without distortion, they cannot be reduced to a single numerical scale (Sen, 2017). Although Martha Nussbaum formulated a set of 10 'central human capabilities', in doing so, she departs from Sen's articulation of CA in that he does not endorse a minimum set or conditions of capabilities but rather stipulates a framework and key set of terms on which nation-states develop their minimum central requirements for well-being.

Nussbaum acknowledges care as a central plank of her capabilities approach (Nussbaum & Levmore, 2017) and caring contributes to people's capabilities, functioning, and well-being

(Agarwal, Humphries, & Robeyns, 2005). Therefore, within the list of ten central human capabilities are specific items directly relevant to an account of care and well-being. These are highlighted below:

> **Emotions.** Being able to have an attachment to things and people outside ourselves, to love those who love and care for us, supporting this capability means supporting forms of human association that can be shown to be crucial in their development.
>
> **Affiliation.** Being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction, to be able to imagine the situation of another. Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation. (Nussbaum, 2011)

Nussbaum articulates affiliation in terms of "Being able to live with and toward others, to recognise and show concern for other human beings,' and 'having the social bases of self-respect and non-humiliation', protecting this means 'protecting institutions that constitute and nourish such affiliation." (Nussbaum 2011, p. 34). A further extension of the CA to care is provided by Kimberley Brownlee (2020), who provides an important contribution to care and well-being theorisation, outlined in the section below.

In her recent book *Being Sure of Each Other,* Brownlee aims to contribute to justice orientated discussions of human sociability. Brownlee develops work by Wolff and De-Shalit (2007) to argue for two essential features of a justice informed account of human sociality and well-being: 1) A minimally adequate access to decent human contract and connection and 2) That being human means, first, having a deep interest in offering our care and company to others – what are called 'social contribution needs' that is to be able to contribute to specific other people's survival and well-being (Brownlee, 2020, p. 16). She argues for an idea of well-being beginning from the basic concept of 'belonging' (op cite, p, 17). Developing this account, I suggest that caring relations are constitutive of functionings. They facilitate functioning, and in this way, they can be understood as a type of primary good and essential to human well-being.

To recap, care relating to well-being is identified by Nussbaum as *affiliation* and by Kimberley Brownlee as *belonging*. Unpacking the capability in terms of the need to belong and responding to criticisms levelled against Nussbaum's account of well-being, Brownlee argues that it involves more than our *ability* to 'live with and toward other people' in conditions of mutual care. It includes 'our positive exercise of those abilities' (Brownlee 2020, p.14). In this way, caring relations can be understood as constitutive of functionings, and facilitate functioning, in the same way as a type of primary good and are therefore essential to human well-being. Well-being and care theorisation, therefore, must begin from a relational perspective. A relational articulation of care is fully theorised in an ethics of care account and is elaborated further in the next Chapter Three.

Secondly, the CA to care emphasises sociopolitical features that impact caring outcomes. The CA emphasises not just what people can do but also their freedom to choose and have and lead the kind of lives that people have reason to value. It begins by asking, "What is the actual living that people manage to achieve?" (Sen, 2001, p. 74) and in responding to this question, freedom is an essential precept. A central tenet of the capabilities approach is the idea of 'substantial freedom'. This is explained as a set of (usually interrelated) opportunities to choose and act (Nussbaum, 2011). These freedoms provide opportunities but are acknowledged as created by a combination of personal abilities and the political, social and economic environment. Sen (1999) conceives of individuals or agents as; "The agency role of the individual as a member of the public and as a participant in economic, social and political actions" (Sen, 2001). In this regard, we can understand Sen's conception of agency and human nature itself as very much belonging to the Aristolean eudaimonic well-being tradition and connected to the idea of sociality.

Significantly for a discussion on family care, the idea of a social conception of responsibility that Sen puts forward does not diminish the role of personal and individual responsibility. On the contrary, he asserts that there is no substitute for individual responsibility denouncing that the idea of substantive freedoms leads to 'a nannying state' where individuals have no part to play in the responsibility for their well-being and, relatedly, their families. Instead, Sen encourages a conception of freedom that understands the individual agent as involved in the process of decision making to achieve opportunities for valued outcomes and that; “Responsibility requires freedom.” (Sen, 2001, Trystan, 779).

Freedom is essential to our discussion of unpaid care and well-being; as discussed previously, care is understood as a political and social construction. Therefore, accounts of carer freedom need to acknowledge the broader role of socio-political influences. I argue that the orientation of CA towards broader structural in origin influences on capabilities is particularly appropriate for an exploration relating to family carers. This is because carers capacity to enjoy substantial freedoms can be understood as curtailed or even damaged because of expectations to care that are normalised and enforced through sociopolitical systems and norms.

The theoretical discussion highlighted above, shows how the implications of the CA for an understanding of care pivot around the key issues relating to agency, freedom and responsibility. As outlined above by Austin (2018), the hedonic, monistic view of subjective well-being derails the sociality inspired by the conception of well-being originating with Aristotle, which acknowledges sociopolitical influences. This is particularly crucial in the case of care as (and as outlined in the Introduction and argued in the forthcoming section on care theory) care is understood as a political and social construction (Daly, 2002). If we conceive of well-being in the context of care as pluralistic incorporating multifaceted social and relational aspects, then it is possible to understand the socio-political contexts in which well-being outcomes may be situated.

The third reason the CA approach to well-being is particularly salient for understanding well-being in the context of care is because it begins with a commitment to social justice. The argument was made in the previous discussion that accounts of well-being based on subjective utility satisfaction fails to acknowledge the discrimination or oppression that certain groups or individuals can face because of external background factors. Moreover, subjective well-being measures can also skew or conceal inequalities. Nussbaum argues that claims about fundamental entitlements to well-being are to some extent independent of the preferences that people happen to have, choices shaped, often, by unjust background conditions (Nussbaum, 2003). The inequalities that carers experience can be understood as a result of unjust conditions created and sustained by socio-political and individual factors. As Hick notes, “Since what people can do and be is inherently plural, the capability approach offers a framework which is unambiguously multidimensional, focussing on the many ways in which human lives are impoverished.” (Hick, 2014). In relation to family carers, the capability to choose is shaped and conditioned by a range of more expansive and social, political and cultural structural factors.

Furthermore, the capabilities approach to well-being offers a set of objective ‘capabilities’. The expansion of capabilities available to individuals should be the aim of public policy (Nussbaum, 2011). Nussbaum (2003) argues that the Rawlsian idea of ‘social contract theory of justice’ assumes equality and has no space for dependency or vulnerability and reasons for the need for care to be included in the Rawls list of primary good (op cite, p55; Kittay, 2002). Sen points out that resource-centric approaches to understanding inequality are deficient because people have different needs and require various resources to achieve the same capabilities (variations he calls ‘conversion factors’). The approach insists on distinguishing between resources, which are considered only of instrumental importance, and capabilities, which, Sen argues, are of intrinsic importance (Hick, 2014). Nussbaum asserts that the CA ascribes an urgent task to government and public policy to improve the quality of life for all people, as defined by their capabilities.

Understood as a social justice theory, the capabilities approach represents a marked shift from previous well-being theorisations. It has gathered approval globally, and it is contained within the Millennium Development Goals, which include aspects of equality and fairness among its goals and the improvement of collective well-being. As Krishnakumar and Nogales note, just distribution remains the common goal that underlines conceptions of well-being as multidimensional (Krishnakumar & Nogales, 2015). In its application to well-being and unpaid care, the CA represents the most appropriate theoretical framework to explore well-being in the context of care because of its emphasis on justice and the idea of collective well-being. Carers of older people experience particular forms of inequality based on a series of intersecting factors that relate to their identity and position as an unpaid carers. A theory of well-being, therefore, requires the recognition of equality and social justice from the outset.

Moreover, the CA situates ideas of well-being firmly with issues of social justice because of the very fact that family carers experience (across all domains) poorer well-being outcomes. Therefore, there is a growing recognition of the need to ontologically frame care as a social justice issue (Williams, 2018). It is argued here that the CA provides a particular set of foundations that are particularly helpful in this regard.

2.8 SUMMARY

To summarise, I have so far outlined significant theoretical aspects of the CA to well-being, and how they are relevant to discussions concerning care of older people, these are summarised below:

- CA accounts for relationality particularly important in accounts of care given the relational nature of care itself.
- Care is a secure functioning understood as an essential feature of well-being
- The idea of 'substantial freedoms' - what each person can be and do enables an examination of carer well-being that acknowledges socio-political features and the relational contexts that influence the opportunities for substantial freedom. Thus, the ability to pursue goals that one has reason to value is situated within and depends upon structural and relational factors.
- CA provides a justice inspired perspective on exploring and accounting for family carer well-being and inequality experienced by many family carers.

2.9 CRITICISMS OF THE CAPABILITIES APPROACH

Criticisms have been levelled against the CA, and I focus on these and apply them to discussions concerning family care. Firstly, it is at the point of combining the different capabilities that Nussbaum's work has been subject to intense criticism (Engster, 2015; Kittay, 2011). Engster argues that Nussbaum's 'central capabilities list' understood as a kind of minimal threshold for capability development, is problematic and can be understood as stigmatising - those who cannot achieve functionings are deemed; "A tragedy…at one extreme, we may judge the absence of capability for a central function is so acute that the person is not a human being at all." (Nussbaum, 2000, cited in Engster, 2015, p. 177). The charge against Nussbaum's list is valid in the context of this study's focus on care of older people, who are by reference to their older age more likely to experience impairment and challenges to functioning. Engster (2015) describes the implication of Nussbaum's 'central capabilities' as describes; "The dark side of this evaluative conception of human functioning is that it devalues the lives of all people who fall short of the human threshold in any of her listed capabilities areas." (Engster, 2015, p. 177). Nussbaum's capabilities approach, therefore, founded upon the idea of a "species norm" (Nussbaum, 2011, p. 179), is particularly problematic, and in relation to care of older people, I argue this can be seen to instil a form of the medical model of ageing. Sen's more elastic and locally contingent sense of which capabilities count is arguably better placed to accommodate the particular position of family carers and those they care for.

Relatedly, Nussbaum's objective list of capabilities has been criticised for devaluing individual agency and implies implicit paternalism (Sugden, 2006). Refuting this, Austin (2020) highlights that the CA begins from the central idea of freedom as a constituent of all capabilities, therefore, leaves room for agency and self-determination. As discussed above, according to Sen, the main principle of substantial freedoms emphasises agency and self-determination. To summarise, according to the CA, responsibility does not diminish agency or result in paternalistic policy formulation. Instead, it highlights a plurality of ways individuals have prospects for or diminished opportunities to realise well-being.

Secondly, the CA has been criticised in relation to an apparent imprecision of meaning with regard to the two term's 'capabilities and functioning's.' This charge has been developed into a CA account that circumvents the problems mentioned above concerning care of older people and are adopted within this study's theorisation and are outlined next below.

2.10 DEVELOPING THE CAPABILITIES APPROACH - 'SECURE FUNCTIONINGS' VULNERABILITY AND RISK

Sabine Alkire (2005) charges the CA with a lack of clarity, noting that capabilities seem to be engaged in observing possibilities, not realising functioning's (Alkire, 2005). This, Alkire argues, serves to dampen and confuse the terms. Wolff and De-Shalit (2007) acknowledge this criticism and, in doing so, depart and develop Sen and Nussbaum's CA framework. The authors note that capabilities as understood as opportunities for functioning, also referred to as 'freedoms' are vague and incomplete, and they replace it with the idea of; "Genuine opportunities for secure functioning's." (Wolff & De-Shalit, 2007, p. 37). Furthermore, Wolff and De-Shalit's position to be able to care and be cared for is fundamental to wellbeing; "Being able to care for others is part of being a person, at least under normal conditions, and therefore part of one's well-being." (Wolff & De-Shalit, 2007, p. 37). The idea of secure functionings is based on freedom and choices, which they argue are typically associated with costs and risks, but these ideas are not contained within the original CA based upon Sen and Nussbaum. Wolff and DeShalit argue, therefore, that achieved functioning's should not be the sole measure of well-being, noting that; "In their zeal to emphasise freedom to achieve functionings, CA theorists have failed to recognise the issue of sustainability and risk". (Wolff & De-Shalit, 2007, p. 65). Thus, the idea of secure functionings acknowledges that some functionings may come with risk. In this study, the theorisation of 'secure functionings' is acknowledged as critical to carer well-being as it recognises the risks and uneven outcomes that carers experience.

A final criticism relates to what some theorists have called a deficiency in the CA related to its immeasurability (Deneulin & McGregor, 2010; Robeyns, 2005). Contemporary CA theorists, however, point to the CA applied within policy contexts. For example, in the UK, the CA has provided a framework for the Equality and Human Rights Commission In Equality Measurement Framework, developed by leading CA theorist Tania Burchardt and Penny Lizzard (Burchardt & Vizard, 2011). This framework provides a validated tool that could be adapted to determine the well-being outcomes of family carers of older people. Furthermore, Yerkes et al. (2019) have developed and applied a framework for operating the CA in social policy settings. This account, I suggest, recognises well-being as normatively individualistic but provides a method that is sensitive to the complex effects of social and political structures and the interplay between these and individual agency. In their discussion, the authors provide a detailed account of the CA to the relationship between agency and structure and the process of converting capabilities into functionings.

Building upon work by Sen, they distinguish between types of relational and structural factors that impact and can be understood to influence an individual's ability to translate resources into real opportunities (Yerkes, Javornik, & Kurowska, 2019). Sen theorises these factors and further operationalised in Yerkes et al. account (2019) as 'means' and 'conversions'. Firstly, means are defined as social and economic resources, including social and welfare policies. Secondly, 'conversion factors' are the social, economic and cultural contexts in which the individual is situated. Conversion factors are the contextual and relational aspects that shape our ability to translate capabilities into real opportunities. (Yerkes et al., 2019). Concern with conversion factors reveals how structural factors influence an individual's ability to achieve valued functionings. This framework represents a practical application of the ideas put forward by Sen and Nussbaum, and I argue it provides a persuasive and robust account of why carers experience unequal well-being outcomes and a suitable foundation on which to address this study's focus and central question.

2.11 CONCLUSION TO CHAPTER TWO

This chapter set out to respond to the question; **How is well-being understood in the context of family care of older people?** Theories of carer well-being in the context of ageing have, up until recently, been principally concerned with documenting the burden and adverse well-being outcomes that carers can experience as a result of care, and mainly draw upon key theoretical burden models that are outlined in further detail in the section below. It traced the philosophical routes of the concept in order to understand the normative values that underpin the contemporary application of well-being. The idea reflects a particular hedonic approach characterised by reliance on happiness and subjective well-being measures in the UK. The problems associated with a hedonic account were outlined, and I presented the CA to well-being as a promising fit to examine the well-being of older people's family care. Although the CA acknowledges relational personhood argued by theorists as pivotal to understanding well-being (Brownlee, 2020, Wolff and De-Shalitt, 2007) through examining the ideas of substantial freedoms, care as a social and political construct can be explored.

Although the CA is ultimately focused on the individual, the context in which any such analysis is set or achieved well-being is inevitably social. While it is normatively individualist, it is, of necessity, methodologically sensitive to the complex effects of social structures and the interplay between these and individual agency. The widespread use and proliferation of well-being as a political value and a policy tool on which to configure service support for carer requires a social and political theoretical framing, and I suggest that the CA to care and well-being offers a practical and robust approach on which to examine and explore these issues in greater depth. Furthermore, it supports a social justice informed account of well-being in the context of care.

Having established the first theoretical pillar for an account of well-being in care, in the next section Chapter Three, I critically engage with family care theory and how it is understood within contemporary thought. Finally, I argue that the feminist ethics of care approach provides a suitable theory on which to understand well-being in the context of older family care.

CHAPTER THREE – THEORETICAL FOUNDATIONS OF FAMILY CARE

3.1 INTRODUCTION TO CHAPTER

This section examines care theories, explored in relation to older people, and draws upon critical theoretical discussions originating in the gerontological, sociological and political-philosophical scholarly work. This discussion does not attempt to synthesise this significant and often disparate body of care theory work. Instead, the intention is to offer a clear argument that supports feminist and political ethics of care theorisation of well-being in older age care. The task of this current section is therefore twofold: 1) To outline the key theoretical constructs used in contemporary family care theory relevant to older age care and 2) To identify a theoretical account that is appropriate for theorising well-being in the context of care of older people. In contrast to theories of care that aim to examine the interactional and personal care activities (Conradi, 2019), I focus on the structural accounts of care theory, reflecting this study's central research attention on responding to calls for sustainable solutions to carer inequalities. Thus, this section seeks to explain how care is provided at structural levels and how these structures and processes are linked to unjust care conditions and inequalities.

The review findings inform the analytical framework and an emerging argument that the contemporary feminist ethics of care approach is the most appropriate starting point for understanding carer well-being. This argument rests upon three broad ideas: 1) The evidence of unequal outcomes experienced by family carers requires a justice informed account of carer well-being. 2) An emphasis on relational care allows an understanding of care that is contextual and highlights the significance of extrinsic support and understood as essential to promoting and sustaining carer well-being. 3) There is substantial value in applying an understanding of relational older age care, which challenges the dyadic relationship of care and is framed as burdensome and individualistic. I subsequently apply the conceptual framework developed in this section (and informed by the previous section theorising well-being) to analyse the 1) empirical literature on outcomes of care on carer well-being (see next chapter) 2) policy application of well-being in the context of care using a case study example

(Social Services and Well-being Act Wales 2014) and 3) the primary data gathered for the study in the form of semi-structured interviews (Chapter Seven).

The current chapter is structured as follows: firstly, it outlines problems associated with defining care and issues relating to the carer dyad, I highlight the non-confining broad and political account of care provided by Fischer and Tronto (1990) as a plausible definition on which to explore well-being and care in the context of old age. I then outline the main features of care theory, including family care as an idealised type of care and its relationship to gender. Here I introduce care ethics as a suitable account of care that can respond to the injustices of care highlighted by feminist scholars. Next, I provide a detailed discussion of care ethics as an alternative justice informed account of carer well-being and highlight key theoretical features relating to dependency and vulnerability. Finally, I sum up by presenting an analytical framework that merges the CA to well-being and ethics of care approach to care.

3.2 DEFINING FAMILY CARE

In this section, I explore the concept of care as it is normatively and ontologically understood and embedded in all aspects of social life. Reflecting the ubiquitous nature of care, care theory originates and spans disparate disciplinary roots, including; gerontology (Anderson, Keating, & Wilson, 2017; Barnes, 2011; Barnes, Brannelly, Ward, & Ward, 2015; Keating, Fast, Lero, Lucas, & Eales, 2014; Keating et al., 2021; Twigg, 2000; Vlachantoni, 2019; Ward & Barnes, 2016); sociology (Daly, 2002, 2020; Yeandle et al., 2012) and has been applied to economics (Dowling, 2020; Himmelweit, 1995), welfare regimes (Daly, 2012) and migration (Baldassar, Ferrero, & Portis, 2017). Therefore, there are unsurprisingly many definitions offered by and within the scholarly literature. Three distinct paths have been identified to understand care 1) care as a feeling or disposition, 2) care as work and a physical practice and 3) care as a social relationship involving power and dependency. These broad facets of care theory offer distinct insights and have a common concern to address how care interacts with social life, individuals and structural contexts (Rummery & Fine, 2012).

In the UK, early theorisations contributed to understanding care as uncommodified work anchored in kinship duties and obligations (Daly & Lewis, 2000; Thomas, 1993) and were typified by a unidirectional relationship in which an independent caregiver provides care to a passive care receiver (Finch & Groves, 1983). Contemporary care theorist Keating et al. (2019) defines family care using two main domains: 'care as doing' and 'care as being in a relationship'. (Keating & Eales, 2017b). These accounts of care provide analytical frameworks for identifying outcomes of care on carer well-being and increasingly refined measures of well-being failures. However, theorists such as Purkis and Ceci (2014) raise important questions concerning how care is problematised in the theoretical literature. The authors ask why this extant academic literature has had a little appreciable impact on strategies to support carers providing care at home. The authors note that this is undoubtedly politically derived, but they also argue that it is partly due to the lack of problematisation around the concept of care (Purkis & Ceci, 2015). A similar point is made more recently by leading care theorists Sophie Bourgault and Fiona Robinson (2020), who note rising inequalities and power differentials between groups, and the need therefore for a political account of care. (Bourgault & Robinson, 2020). I turn now to discuss further problems with defining care before highlighting the political description of care provided by Fischer and Tronto (1990) that is applied throughout this study.

3.3 FAMILY CARE AS 'GOOD CARE'

Broadly, a historical and unifying feature of care theorisation was the articulation of care comprising of two primary actors - the cared for and the carer. Early studies conducted by Finch and Groves (1983) depicted older age care as unidirectional focused on the carer and the cared for. This characterisation of care rests upon the idea of the carer dyad. The carer is an active and independent caregiver, supporting a dependent, passive care receiver (Finch & Groves, 1983). Carer-giver-care recipient dyad has been considered by researchers as the appropriate object of enquiry and particularly in the North American context; as Purkis and Ceci (2015) argue, this reflects the strong ideology of individualism, assumptions of norms of independence and responsibility for self and kin (Purkis & Ceci, 2015). The early carer dyad theorisations have been heavily criticised, stemming mainly from disability scholarship (Oliver, 1996) that challenged the care receiver in the dyadic relationship as reductive and objectified, reduced to mere dependence and without a voice (José, 2016). Countering these criticisms, gerontologist Julia Twigg (1998) refutes that carer dyad underwrites the dependency of disabled people by arguing that carers needs must be recognised in their own right and as a group vulnerable to oppression and discrimination (Twigg, 1998). Nonetheless, these critiques underscored that the cared-for contribution to caring is not incidental and must be given due attention, as Michael Fine notes the challenge to the carer dyad at the very least; "Provided a necessary antidote to the tone of moral superiority that had crept into many of the accounts of care as a burden." (Fine, 2013, p. 426).

Feminist care ethicists proffer a relational account of care that can be understood to attend to the deficiencies of the dyadic relationship. In this study, I follow the broad, all-encompassing definition of care provided by care ethicists Fischer and Tronto (1990), who define care as; "A species activity that includes everything that we do to maintain, continue, and repair "our world" so that we can live in it as well as possible." (Fisher & Tronto, 1990, p. 19). This definition is selected for this study because it supports a collective, broader and relational understanding of care.

As outlined in the previous section on well-being theory, I argue for identification of care as a functioning (the various things a person may value doing or being - our well-being outcomes), and this is grounded in an account of human nature that is characterised by our 'relational personhood' our need to care and be cared for. A relational understanding of care posited by care ethicists reveals the complexity of care situations that cannot be separated and divided by the dichotomous relationship of the carer dyad. Relationality requires an appreciation of care that happens in a pluralistic web of relations that relate to social, political and cultural contexts and is elaborated further sections below.

Care is situated within a wider normativity of family care and kinship care that has dominated care theory in North America and Europe (Fine, 2012). Much of this normativity in western nations and since the 1950s can be traced back to sociological theory originating with American structural-functionalism of Talcott Parsons and the idea of the 'nuclear' family. (Korgen, 2017). Here we can understand that the concept of kinship care and the importance of the 'nuclear family' is a necessary condition of industrial capitalist systems (Twigg, 2000). Early illustrations of the 'care in crisis' discourse can be understood as related to early theorisations of care that warned that broader kinship ties of reciprocity and care have withered away (Twigg & Atkin, 1994). This crisis discourse justified a withdrawal of state-funded support for care (Kosberg & Cairl, 1986) and led to unresolved tensions regarding the question as to whether formal care services ‘crowd out’ family care, and this has been an enduring feature and issue in the care literature (Bertogg & Strauss, 2018). Countering these claims, empirical studies in the early 1980s showed that families (predominately women) continued to provide the majority of unpaid care (Kosberg & Cairl, 1986).

Moreover, recent evidence suggests that formal and family care can complement each other (Balia & Brau, 2014; Bertogg & Strauss, 2018). Across Europe, there is evidence of combined models of family care and state-supported care (Buckner & Yeandle, 2015). However, contemporary care theorists highlight a continual trend of diminished state-funded support to care across Europe and North America and highlight this as compounding carer inequalities and burdens (Williams, 2018).

Despite the evidence of complementarity noted above, the pervasiveness of family care as the preferred means of support is reflected in early attempts by care theorists to provide definitions of care. In the UK, these definitions focused on the private family domain. In contrast, in Scandinavian countries where a different welfare provision for care exists (state-based), the purpose of care and carer are based on care in the public domain (José, 2016). Moreover, contemporary care theorists point to the primacy of an ideal of ‘family care’ evidenced as enshrined implicitly or explicitly within recent social care policy systems in western democracies (Cash, Hodgkin, & Warburton, 2013; Kodate & Timonen, 2017). These systems conceive the wife as fundamentally performing reproductive labour within the household, childrearing, caring and homemaking and the man providing the pay-check (Tronto, 2013). They rest upon an enduring norm of the ‘nuclear family’, noted by feminists as implicit within post-war welfare state systems (Lister, 2018).

Feminists highlight the ‘myth of the nuclear family’ today and that more and more women are participating in paid employment within contemporary society. Despite these structural changes, however, women are caught in a “second shift” (Hochschild & Machung, 2012), where a gendered normativity of care results in women performing the majority of family care work alongside paid work outside of the household. Relatedly, recent care theorists evidence how working conditions and career paths in contemporary societies are organised around the ideal of citizens, as autonomous and independent, with little acknowledgement within formal legal frameworks of workers caring responsibilities within the household (Moen & DePasquale, 2017). The interaction between the cultural expectations and norms in relation to responsibilities to care and structural systems, care theorists argue, result in burden and strain, and account for carer inequalities (Folbre, 2008; Urban & Ward, 2020; Williams, 2018).

The pervasiveness of the ideology of family care (and women) as the primary providers of support and preferred means of support raises essential questions concerning care freedom and choice. These concepts are a reoccurring theme in caregiving literature. Arguably, family carers may experience a lack of freedom because of the enduring nuclear family norm. Highlighted in the well-being theory section through the idea of substantial freedom articulated by capabilities theorists, freedoms provide opportunities. However, they are acknowledged as created by a combination of personal abilities and the political, social, cultural and economic environment (means and conversions). Studies show marital or family obligation is a common motivating factor behind carers providing in-home care, and this obligation, it is pointed out, is situated within the complexity of political, moral and or social responsibility that is located within social and cultural constructs and expectations (Andruske & O'Connor, 2020; Saraceno & Keck, 2010). In addition, choice can be understood as enforced and enacted through legal and policy contexts. Although in some countries, family support laws oblige adult children to support their ageing parents in the UK, families are not required by legislation to provide care and support to older relations. In the UK context, the obligation to care can be understood as entrenched by the broader operations of a highly marketised, unstable provision of older age care (Needham et al., 2018), offering limited options, choices or alternatives to family care.

Care theorists have highlighted the adverse well-being outcomes experienced by carers if care is given unwillingly. In this situation, it is argued, care can induce subjective negative well-being states such as resentment and guilt in both giver and receiver of care (Qureshi and Walker, 1989). A recent study provided by Cash et al. (2013) challenges the normalcy of family care as good care. The authors point to evidence that shows how the impact of family care can weaken kinship bonds. Concerning ideologies of family care permeating welfare solutions, these solutions can become counterproductive (Cash et al., 2013). Relatedly, Rand, Malley and Forder (2019) found that reasons for caring were essential predictors of well-being and strain. The authors found evidence of lower well-being scores related to when people were carers because social services suggested it, or the care recipient would not want help from anyone else (Rand, Malley, & Forder, 2019).

Insights regarding the complexity of giving and receiving within family relations have been explored through the concept of 'ambivalence' by authors, Pillemer et al. (2019). The authors note the relatively scarce literature regarding ambivalence despite a large body of literature that shows that care in family relations can bring about conflicting and negative emotions and outcomes. They argue that the sociological concept of ambivalence supports linkages between social structures, and individual actions in the context of family life and define the concept as broadly referring to tensions, dilemmas and contradictions in family care. The authors suggest that social-structural contradictions can produce carer ambivalence, most notably, pressures due to multiple families and work commitments or roles that compete (in the North American context) with values and norms that promote independence and individualism. The authors conclude that cultural and structural imperatives and the dynamic nature of family circumstances influence ambivalence and its effects on caring outcomes (Pillemer, Suitor, & Baltar, 2019). In particular, and relevant to this study's focus on structurally related carer well-being outcomes, the authors argue that policy discussions need to consider the influence of conflicting demands by social institutions and policies and that policy should view how to reduce sources of ambivalence for carers.

To summarise, care theorists have shown how the family (and female) obligation to care for older adults is reproduced through government-led policies and systems that rest upon nuclear family ideas. These ideals can be seen to be reinforced through inadequate levels of state-provided support for family care that results in a lack of choices for alternatives (state and market) provided forms of support. Moreover, confining care to family denotes it as a private concern. It can be understood to further legitimise limited government forms of care support, particularly within contemporary neoliberal contexts. Research evidence shows how the idea of 'family care as good care' can be challenged, pointing to the ill effects that some family carers can experience because of caring. Therefore, inequalities relating to carers can be understood within these broader normative and sociopolitical structures. In the next section, I look in more detail at the gendered nature of care and relate it to theorisations of well-being for carers of older people.

3.4 CARE, GENDER, WELL-BEING AND AGEING

Gender is essential to understanding well-being in care and has been located within the broader feminist project to reveal and recognise the activities of female unpaid labour (Twigg, 2010). However, the care dilemma is noted as unresolved for both children and older adults requiring care (Moen & DePasquale, 2017). In the UK, recent figures supplied by the ONS show that the most common group caring are aged between 55 to 64 years and comparing women and men in this age group, more women (57%) provided unpaid care than men (43%) (ONS, 2021). The gendered stratification of care has been theorised and examined by feminist's care ethicists (Barnes et al., 2015; Folbre, 2008; Sevenhuijsen, 1998a; Sevenhuijsen, 2003; Tronto, 1993; Tronto, 2013; Tronto, 2017; Tronto, 2015; Tronto, 1990; Ward & Barnes, 2016; Ward & Gahagan, 2010). This work points to a broader disadvantage resulting from caring across the life course (Fredman & Spencer, 2003). Foster et al. note the gendered nature of poverty in older age which reflects women's constrained opportunities across the life course, including the unequal provision of care, its impact on employment, and, subsequently, women's greater likelihood of reaching retirement with inadequate pensions (Foster 2010). Recent government statistics in the UK show that women are more likely to exit the employment market because of caring responsibilities. Women occupying part-time jobs (because of caring responsibilities) are lower paid than full-time equivalents. The report highlights this can lead to lower future pension security and increase the risk of and vulnerability to well-being failures, including social exclusion and poverty in later life (Statistics, 2019). Therefore, women's well-being is linked to the care provided throughout the life course.

Feminist gerontological theorist Toni Calsanti has examined the pervasive impact of care on older women's lives. She highlights, however, a lack of recognition of the potential of feminist gerontology's contribution to knowledge about ageing in broader terms (Calasanti and Slevin, 2001; Calasanti, 2010, Carney, 2000). Therefore, the gendered nature of care in older age has been relatively under-theorised and mainstream gerontological research has been challenged by gerontological feminists as ‘gender blind’ (Calasanti, 2009; Carney, 2017). Similarly, Barnes (2012) argues that care theorisation based upon the feminist political arguments have focused mainly on childcare and women’s struggle for equal employment rights. Only comparatively recently has the situation of women as carers of older and disabled people received a similar level of attention. This work is perhaps the most developed in the UK (Barnes, 2012). Together, this under-recognition of feminist theory in mainstream gerontological thought, combined with a lack of feminist attention given to care in the context of older age, represents a knowledge lacuna and one that this review responds to. I argue that contemporary care ethicists, notably the foundational work provided by Joan Tronto and Selma Sevenhuijsen (2003), can react to these apparent ‘age and gender blind spots’ and support the exploration of care and well-being in the context of older age.

The value of understanding gender as an analytical category on which to understand carer well-being outcomes is essential and has been clearly articulated by feminist care theorists. However, the critical attention to women as primary carers has forgone an appreciation of the male care experience. Only a few investigations seek to analyse men’s contribution to older age care, and there are still several research gaps (Bertogg & Strauss, 2018). I now turn to the increasing recognition of men caring for older people, and in doing so, concur with Calasanti, who proposed that care theories begin from a perspective of *gender power relations* so inclusive of both men and women (Calasanti, 2009).

Recent research indicates that men, especially fathers, are increasingly engaging in the everyday tasks of social reproduction and care (Tarrant, 2018). Figures in the UK show men represent an increasing proportion of family carers. While women have a longer life expectancy, they live a greater proportion of their later years with serious illnesses (Willis, Vickery, & Symonds, 2020). Consequently, surviving spouses may be carers. Recent figures for the UK show that around half of all carers aged between 75-84 years in the UK are male, and are age 85 years, male carers are in the majority. The recognition of evidence of increasing ‘male care’ is leading campaigning groups in the UK such as Carers Trust to recently calling for raising awareness and service support for male carers (Slack & Fraser, 2014).

Despite this evidence, there is a paucity of research focused on the male care experience (Zygouri, Cowdell, Ploumis, Gouva, & Mantzoukas, 2021), and to date, it has been limited and interpreted within the theoretical confines of care and femininity (Kramer & Lambert, 1999; Saito, 2017).

Recent empirical work is provided in the UK by Willis et al. (2020) who examined older male carers caring for an older family member and associations with loneliness and isolation. Based on twenty qualitative interviews with male carers, the authors highlight distinct differences between women and men, with men broadly describing their caring role as less burdensome than women. Furthermore, they conclude that male participants' narratives of their care experiences were diverse and dependent on individual life experiences and caring histories, challenging previous interpretations of men as either ineffective or capable carers. (Willis et al., 2020). These findings confirm the need to understand gender as a category on which to understand well-being in older age care, not least because they highlight the contextual socio-political influences on care that can be understood to affect men and women differently. They also show the damaging effects of the normativity of care as private and individual for families, not only for women. Finally, I suggest that feminist ethics of care theorists provide suitable theoretical foundations for understanding carer well-being. In the next section, I look specifically at how care of older people has been theorised to date before highlighting the ethics of care approach.

3.5 CARE AND AGEING – BURDEN AND INDIVIDUALISM

The preceding discussion highlights that care in its broadest sense continues to be an essentially contested and ambiguous concept; this can be understood advantageously as it can support and highlight its complexity and ethical possibilities (Daly, 2020). As a broad overview, I present that in the context of older age care, two defining aspects can be identified amongst the care literature concerning care of older people; these are 1) burden and 2) individualism and are discussed in further detail below.

Hoenig and Hamilton (1966) were amongst the first to conceptualise care in terms of burden and interpreted the situation of family carers of people living with dementia, using fundamental objective and subjective measures (Hoenig & Hamilton, 1966). After Hoenig and Hamilton's study, an additional and highly influential study was published by Zarit, Reever and Bach-Peterson (1980). The study 'Relatives of the Impaired Elderly: Correlates of Feelings of burden' (Zarit et al., 1980) explored caregivers of people living with dementia. The study produced what is understood to be one of the first instruments to measure caregiver burden, thereafter named the Zarit Burden Interview (ZBI). The ZBI is an important measure to identify and explore concerning this study. It illustrates a conceptual lynchpin (Daly, 2020) that has influenced care theory concerning older people for several decades - the concept of burden. The ZBI comprises a 22 item self-report scale. Much of the later empirical research on care of older people focused on the difficulties and negative limiting ways in which care impacts carers lives and life chances. The ZBI provided a validated instrument is the most commonly used instrument to identify burden amongst caregivers of older people and people living with dementia (Al-Rawashdeh, Lennie, & Chung, 2016; Bédard et al., 2001).

Theoretical work provided by Perla Werner (2012) examined conceptualisations relating to carers of people with mild cognitive impairment, findings based upon a critical review of the literature showed that caregiver burden was theorised in the literature as a multidimensional concept framed mainly within the psychological perspectives of stress and coping (Werner, 2012). Theorising carer well-being concerning burden may be understood as reflecting how care is framed within a broader context of 'crisis' (Daly and Lewis 2000). I argue care for older people, in particular, has had long-standing connections to what is often termed 'dirty work' considered to be physically, morally and socially less attractive (Clarke & Ravenswood, 2019). This can be understood to reinforce and compound negative associations and stereotypes relating to care of older people.

A recent systematic review provided by Cunningham and Cunningham (2019) aimed to explore the specifics of well-being outcomes on carers of people living with dementia. The study draws upon 19 published research studies on caregiving and well-being amongst family carers of people with dementia. The authors note that none of the studies identified discuss the relationship between *intrinsic* aspects of carer well-being – focused on subjectivity and agency – and *extrinsic* factors concerning the material and structural conditions under which care is enacted. Similarly, Moen and Depasquale (2019) argue that too little attention is given to the external and extrinsic factors that influence caregiving in the context of ageing. Instead, most studies report subjective well-being measures and operationalise well-being from burden and stress theory (Cunningham et al., 2018). I suggest that this assumes three things about carer well-being 1) that carer well-being is individualised and private and 2) that care is harmful and associated with decline, disease and degeneration; and 3) that dependency is harmful. Exploring these ideas further through an ethics of care perspective, this can be understood to compound the inequalities of unpaid carers in part to the continued problematising care discourse (Barnes, 2011). I argue this can represent further oppression for carers of older people.

A further review of the conceptualisation of well-being in the context of older age care is provided by Keating et al. (2020). They use a multidimensional account of well-being as material, relational and subjective components (McGregor, 2018) to analyse the literature on unpaid and paid carers to provide a theoretical foundation for well-being within the context of care and applied specifically to the UK public policy. The authors draw upon empirical data relating to carers' well-being outcomes and identify a significant knowledge gap concerning understanding carers' views of their ability or capability to live a life they value. They also note the dominant 'burden discourse' characteristic of the empirical carer data. Furthermore, they highlight the increasing politicisation of carer well-being, citing European Union policy on well-being construed in a way that they argue is 'needs based' and reductive. This account, the authors note, is obscuring the broader normativity of care and how care is set within differential power hierarchies, that particularly in the case of the UK places carer needs and predominantly their need to work centre stage (Keating et al. 2021).

Based on contemporary research, an analysis of well-being in care is required to consider the socio-political arrangements and values that impact how well-being is conceptualised, measured, and experienced. The authors noted this as a significant gap. To this end, the remaining section of this chapter presents an argument for an ethics of care approach to theorising well-being within the context of older age care.

This theorisation aims to extend and contribute to the above-aforementioned work in two specific ways; 1) to engage with broader political-philosophical theories of care and well-being, particularly the ethics of care approach and 2) to identify and attend to the specific aspects of carer well-being that focus on subjective well-being beyond the 'burden' discourse informed by carer's self-reported accounts of well-being and their reflections of it. As outlined, care theorists Purkis and Ceci (201) suggest that there has been a lack of problematisation of care theory, in particular with the carer dyad. I suggest that care theory based upon the burden narrative can too be understood to have done little to dislodge the ageist and individualistic assumptions relating to care in the context of older people. Alternative articulations of well-being failures are required to identify broader relational aspects such as socio-political and cultural features that impact carer outcomes. These two elements, missing from the above-noted studies, informed the central research question; **What does well-being mean in the context of family care of older people, and why does it matter?** In the following section, I map the ethics of care conceptual terrain, highlighting specific foundations that I believe are significant to a theory of well-being in older age care. The section concludes with an analytical framework that is applied to explore the policy application to carer well-being and the study's primary data findings.

3.6 AN ALTERNATIVE JUSTICE THEORY OF CARE – CARE ETHICS

An ethics of care perspective is chosen in this study because it attempts to clarify the nature of care and the role of a specific welfare policy (well-being) in supporting and addressing care needs (Engster, 2015). Ethics of care theory begins from two basic premises. Firstly, care is understood to be fundamentally political - all caring relationships involve power differentials, all care relations are, therefore, according to leading care ethicist political (Tronto, 2013). Furthermore, as political theory care is lifted from its essentialism as women's work and private belonging to the home, and broadened beyond personal relationships; it can be understood to encourage an analytical gaze towards institutional and systemic realities, as Kaver et al. (2014) note; "As political ethics, the ethics of care examines questions of just institutions in a decent society, including the distribution of social benefits and burdens, legislation, governance, and claims of entitlement (Klaver, Elst, & Baart, 2014, p. 760). Secondly, care is relational. It begins from understanding persons as essentially connected and human nature as fundamentally relational. In doing so, as Liz Lloyd notes, "It provides a powerful critique of the moral framework of independence and autonomy as characterised in contemporary policies and practices." (Lloyd, 2010, p. 235).

Broadly acknowledged as beginning with the seminal works by Carol Gilligan (Gilligan, 1982) that provided an affront to the biological essentialism that moral and justice theory is founded upon. In doing so, it critiqued the Kantian, utilitarian and liberal conceptions of the rational, autonomous subject (Gilligan, 1982). The utilitarian concept of the self (described in Section 2.5 above) is understood as independent, autonomous and rational. This conception of human nature has been the subject of intense scrutiny, led by feminist scholarship who refer to 'a myth of autonomy and self-interested, independent, and rational beings'. (Mackenzie, Rogers, & Dodds, 2014). Rather than people standing autonomous and alone, care ethicists understand the world as a series of interconnected relationships, and care as an ethical concept infused with moral and power relations (Tronto, 2015). Care ethics offers a way of articulating and identifying the connectedness of the human experience. The idea of an essential human experience of connectedness can be identified across divergent historical and cultural contexts (Brannelly & Boulton, 2017; McGregor, 2018). In its broadest sense, relationality understands persons as embodied and connected with one and another. In the case of care, the connection is fundamental. Relational autonomy, therefore, challenges the enduring idea that individuals are independent of their social circumstances and able to operate in an autonomous form. “The guiding thought of the ethics of care is that people need each other to lead a good life and that they can only exist as individuals through and via caring relationships with others.” (Sevenhuijsen, 2003, p. 183).

Lanoix (2020) argues that care theory broadly benefits from recognising age because it supports a reconceptualisation of citizenship and accounts for older adulthood. Furthermore, the Rawlsian concept of personhood is idealised as an adult with unmuting and unchanging capacities (Lanoix, 2020). This point has important implications for theorising well-being within the context of older age care because with age comes inevitable changes that more often than not require support. According to ethics of care theorists, care is a universal feature of life that responds to our; “Inevitable dependencies.” (Kittay 2002). Care, therefore, is an essential facet of life. However, in Western societies, care is devalued in favour of independence and self-reliance attributed as crucial features of full citizenship (Lloyd, 2010). It follows, therefore, that if care is devalued, then carers too are devalued, “In contemporary American society, where a great emphasis is placed on autonomous individual life, we perceive neediness as being a burden on those who must help us meet our needs.” (Tronto, 1993, p. 141). Not only is care understood as relational, challenging the dichotomous relationship of carer and cared for, but the connection that care offers, argued by Noddings, can be understood as a contributor to ‘flourishing’, arguing that care enriches our lives as carers (Noddings, 1984). In this way, care can be understood as contributing to well-being as an enriching experience. Drawing from the ethics of care approach and aligned with the previous claim made in the well-being section, care can be understood as a functioning or essential contributor to well-being.

The idea of relational personhood responds to the gaps in our knowledge related to socio-political factors when theorising well-being in older age care. Gerontological care theory can offer essential contributions regarding relationality. Antonucci (1987) and Kahn theorised the life-course social support model; these are ‘convoys of social support’ networks of kin and friends move together through time (Antonucci & Akiyama, 1987). More recently, Moen and

DePasquale (2019) critically engage with Antonucci's model and suggest that social convoys theorised as supportive could also induce strain. The authors argue that family care obligations can result in negative states, especially for wives caring for their husbands. Social care convoys, they claim, are another form of time, norms and activity, representing beliefs and expectations about the appropriate time to be 'spent' in relationships such as in caring for infirm spouses or ageing parents (Moen & DePasquale, 2017). Further applications of relational personhood relevant to care have been developed by authors such as McLeod and Sherwin (2000), who point to relational autonomy in health care settings, noting its importance in recognising forms of group oppression such as sexism and racism (McLeod & Sherwin, 2000).

The relationality account requires exploring well-being in the context of care from a plurality of different perspectives. It importantly recognises the inequalities and oppression that some groups such as carers may experience. For example, Marian Barnes (2012) examines ideas of 'self-determination' in the context of responsibility and care and older people. She identifies a normative value base that divides older people into two groups; the self-determined and the frail (Barnes, 2012). Understood in this way, the extent that carers can be understood as self-determined and autonomous is mediated through their caring role. A relational understanding of care can guide theorisation that does not reduce carer well-being into failure through a lack of self-determination or increasing care needs due to age-related disease. However, the extent to which a relational understanding of care does overcome the aforementioned difficulties, remains contested by disability scholars (Davy, 2019).

Relational autonomy requires seeing persons as interactants (Mackenzie et al., 2014). In this discussion, it serves to expand understanding of how individuals intersect with one and another, and within political and social contexts, it is not confining or reductive and does not simply stand in opposition to individualism (Robinson, 2020). In relation to care of older people, it was noted that the carer dyad theorisation had been the subject of intense criticism. Disability theorists have challenged the carer dyad understanding it as demeaning to the care receiver who were stigmatised as a burden and ignoring the power and voice of the care receiver (Morris, 1993). A relational understanding of care overcomes these difficulties, recognising the need to promote autonomy in the context of vulnerability. Thus avoiding the paternalism and or even coercive social policies or institutions that can compound rather than ameliorate the vulnerability of persons they are designed to assist (Mackenzie et al., 2014).

Empirical evidence consistently shows that as a group, carers are vulnerable to adverse effects because of their caring role, from a relational autonomy perspective and placing carers at the heart of analysis requires a need to be alert to ideas of relational autonomy in response to vulnerability to avoid compounding negative well-being states that derive from states of vulnerability. Furthermore, relational autonomy offers transformational scope for reimagining how carers and those cared for can be supported to care within, what Bowlby and McKie refer to as positive 'caring scapes', an overarching framework in which individuals' "caringscapes" are viewed as dynamically interacting with the resources and services of a "carescape" (Bowlby & McKie, 2019). I argue an essential foundation for developing policy to respond to the 'care deficit' consisting of an increase in older age care demands alongside a decrease in the resource or care capacity to support demand (Brugere, 2020).

In the case of care, where connection is so fundamental, the idea of relationality is of clear value and, as outlined, has been theorised extensively. In practice terms, however, relationality has gained little traction particularly in health care (McLeod & Sherwin, 2000). Furthermore, the fundamental idea of relational personhood has been criticised. Cockburn refers to the care ethics account of relational personhood as a kind of; "Cosy mutuality." (Cockburn, 2018, p. 216). He argues that the emphasis on the relational self cannot solve social justice issues and that relational personhood must not overlook power imbalances. Furthermore, Cockburn argues that our interdependence does not come before social and political institutions and practice – interdependence is given its very form and structure by our basic institutions (Cockburn, 2018). Cockburn's central criticisms can be applied to early care ethicists as detailed. However, the contemporary work provided by authors such as Tronto and Sevenhuijsen advocate and emphasise the critical role of political structures concerning care.

Furthermore, as described, recent gerontological care theory offers new ways of understanding relationality as both positive and potentially damaging to the carer and thus demonstrates that contrary to these charges, relational accounts do not propose a supportive mutuality and can support theorisation relating to social and political influences. Although Cockburn's account of relational personhood appears to miss these vital issues in relation to older age care, it does raise important questions relating to dependence and relevant to care of older people. He notes that, particularly in the case of older people, dependence is understood as non-contributory and that some forms of dependence are culturally stigmatised. In the case of care for older people, there is clear evidence suggesting that carers, particularly those caring for people living with dementia, experience discrimination and stigma (Ayalon & Tesch-Römer, 2017; Lim, Ahn, & Ahn, 2016; Zwar et al., 2021). These issues are significant to carers of people living with dementia, as they are vulnerable by association to this discrimination. In the next section, I discuss two vital aspects of care ethicists theory of care vulnerability and dependency and highlight why these are important in theorising carer well-being in the context of care for older people.

3.7 DEPENDENCY AND VULNERABILITY

The very nature of care implies a type of dependency, and this has been theorised and understood for several decades amongst care theorists. This dependency has been problematised as described above, particularly concerning stigmatising the cared for within the carer dyad. Initial care ethical theory sought to demonstrate how dependence was part of the human experience. Kittay argued a valorisation of independence through the denial of dependence results in insufficient public policies (Kittay, 2013). Tronto offers macro-level insights into how dependency operates as a concept within political economies in the West and how most democratic political theories assume the existence of independent, autonomous actors as the starting point for democracy (Tronto, 2013). Following this line of argument, dependency, therefore, can be understood as a type of individual failing or flaw and in Western welfare regimes, some political theorists suggest dependence has become synonymous with immorality and injustice (Cockburn, 2018), the resultant stigmatisation of welfare support can be understood to justify welfare retrenchment .

Cockburn explores the issue of dependence in relation to vulnerability and argues that in the context of western welfare systems, economic dependence can result in individual and group *vulnerability*. To be dependent is also to be vulnerable to the withdrawal of support, and this kind of vulnerability is something that particular social groups have suffered much more than others (Cockburn, 2018). I suggest that this framing of dependence with the idea of vulnerability is particularly applicable to carers, who can be understood as dependent on support (in it's broadest sense including economic, social and practical support) to care therefore vulnerable to harm. I suggest that the concept of vulnerability rather than burden offers a broader and political account of carer well-being than the individualised theorisation that rests upon burden. A detailed examination of vulnerability and care is provided in the following section drawing upon contemporary care ethicists.

Leading feminist legal theorist Martha Albertson Fineman (2010) argues that the problem of dependency as a temporary state often implies that policies to remedy dependency can be made by appealing to private (family) relations to support, thereby denying state or government role in providing care and support (Mackenzie et al., 2014). Interrogating the idea of dependency further, Daniel Engster (2018) argues that the state of being dependent is problematic for political theories of care and justice because dependency implies a temporary and episodic state. However, caring for many can be a lifetime experience, and caring episodes can be understood as reoccurring throughout life (Walsh, Scharf, & Keating, 2017). Extending Fineman's ideas of universal vulnerability to care ethics, Engster notes a tendency to use the terms dependency and vulnerability interchangeably. Engster responds to this by distinguishing between vulnerability and dependency; "Dependency is a form of vulnerability where individuals are highly susceptible to imminent harm…vulnerability encompasses real and potential threats to our well-being that arise from being in the world and living in relation to others." (Engster, 2019). Engster argues recasting care in terms of responding to unwanted forms of vulnerability expands its scope and overcomes the problems of dependency and need as confined to private (family) care.

Tronto's fifth element of care, 'caring with', argues for a communal and collective responsibility for care, but as Engster argues, without a fully formulated notion of care that includes vulnerability, it is difficult to widen its scope. Engster argues that caring about people's vulnerabilities and susceptibility to harm implies that we should not only have a concern during periods of dependency but also that may afflict them throughout their lives, including those we generate through our communal institutions and norms (Engster, 2015, 2019).

This line of argument appears particularly compelling applied to theories of carer well-being. The evidence of care inequalities underscores the need to recognise carers vulnerability to harm. Moreover, the idea of a universal vulnerable state can also be seen to address the inherent power differentials between the carer and the cared-for; as Brugere notes; “Addressing vulnerability means not losing sight of the care recipient’s ability to be productive: assistance should not be confused with charity.” (Brugere, 2020, p. 153). As Fineman argues, ‘vulnerability’ is experienced universally by all human beings and is a continuous enduring state. It is contended that a vulnerability analysis, rather than a dependency frame, may prove more theoretically decisive in upending the dominant liberal discourse and mobilising broad support for a more responsive state (Fineman, 2010).

Feminist political philosophers have argued that many forms of vulnerability are caused or exacerbated by social and political structures. Mackenzie et al. (2014) introduce a taxonomy of different sources and states of vulnerability, which they argue enables a finer-grained analysis of its ontological and context-specific dimensions. Mackenzie et al. conclude by highlighting the prominence of vulnerability in accounts of social justice and that the capabilities approach provides the most promising theoretical framework for articulating this claim and promoting democratic equality (Mackenzie et al., 2014). The conceptualisation of vulnerability is essential in discussions concerning care and well-being because care is attending to forms of vulnerability, and carers themselves can be identified as both vulnerable and dependent because of their caring status. Therefore, a vulnerable conception of agency encourages a degree of state responsibility to support and lessen the adverse well-being outcomes of vulnerability to harm.

3.8 THE INDIVIDUALISM OF CARE, NEOLIBERALISM AND ‘SELF-CARE’

As detailed previously, family care is understood politically in the UK, as the preferred and prized means of support given to older people. However, evidence of deepening inequalities experienced by family carers points to a concerted effort on the part of care theorists to tackle issues of social justice relating to care (Engster, 2015). Ethics of care theorists provides social justice account of care. I now turn to elaborate the ethics of care perspective on issues relating to care and justice and apply these ideas to carer well-being.

Tronto and Fischer (1990) explore care in close relationship with ideas of justice, citizenship, democracy, and equality and supply four critical principles of care: 1) 'caring about', which requires attentiveness; 2) 'taking care of and responsibility for care; 3) 'care giving' the tasks of care requiring competence; and 4) care-receiving (Fisher and Tronto 1990). In part in response to the 'crisis of care', Tronto has since added a fifth element to the phases of care, defined as 'caring with' Tronto (2013), and this is understood to provide a collective responsibility for nurturing and supporting care. Tronto (2013) developed earlier work by Selma Sevenhjuisen (1998), who contends that a caring, democratic society includes a commitment to consider the moral complexities of dependency, vulnerability and otherness that require plurality, communication, trust and respect. In 2004, Sevenhuijsen (2004) designed the 'trace' method to evaluate policy texts. Using this method, she interrogates the Dutch policy document 'Choices in Health Care'. This method has been employed in the subsequent Chapter 4 – policy analysis.

Sevenhuijsen (2004) reforms ideas about justice placing care alongside politics and justice, and challenges Rawlsian ideas of redistributive justice. Sevenhuijsen argues that a caring democracy requires collective responsibility, claiming that solidarity without care leads to an impoverished sense of morality. Caring solidarity is needed because everyone in different ways and to different degrees needs care at some point in their lives. The universality of the caring experience thus requires a political effort and will to enhance, protect and provide care for all.

Tronto's theory of 'caring democracy' holds much promise as an analytical framework to respond to the broader context in which this study is located; the 'care crisis'. In *Who Cares* (2015), the fifth phase of 'caring with' is explained in response to inequality;

> *"Any given act of care is unequal. But across generations, and across any given person's lifetime, we can set a democratic goal to even out these inequalities so that*

> *there is an 'ongoing pattern of care', consisting in the reciprocal ways in which, over time, care is given and received between citizens."* (Tronto, 2015, p. 14)

This fifth phase of caring involves a transformational rethinking of democracy and political theory with an argument presented that shows the limits and harms that contemporary neoliberal economic and political systems present to care theory and citizenship more broadly; "From the standpoint of an ethic of care, neoliberalism is a disastrous worldview." (Tronto, 2013, p.38). Tronto asserts that care is essential for democracy but that under current neoliberal government systems, democracy is undermined (Tronto, 2015). As a broad concept, neoliberalism refers to a form of free-market capitalism and economic liberalism (Doidge & Saini, 2020). It is generally accepted as an ideology that emphasises an individual's responsibility, self-management, and economic independence regardless of social circumstances (Chandler, 2020). It is understood as devaluing the role of structural factors affecting people. It is characterised by privatisation and an emphasis upon the individual and the family to take responsibility for the vulnerable (Brugere, 2020). Leading care theorists explore the idea of responsibility for care through what is termed the 'individualism of care' (Lloyd, 2010; Lloyd et al., 2014). The concept of the individualism of care is critical relating to carer well-being; as care theorists posit, governments present individualism as an extension of personal choice (Hayes, 2017).

The individualisation of care is a process that leading theorist Fine notes as incomplete, ongoing, fiercely contested and still open-ended (Fine, 2013). In relation to public service provision, it is of itself, widely acknowledged as positive and progressive; however, its prominence as a value on which to base service provision is questioned in relation to evidence of deepening inequalities and increasing demand for care; "Yet, despite its potential, the term is often abused in its reduction of the concept of individualisation to market-based consumer choice and the hidden exploitative approach to care workers and unpaid caregivers." (Fine, 2013, p. 433). Drawing upon foundations provided by ethics of care theory, Fine highlights that care and individualism appear diametrically opposed; care is concerned with the well-being of others and is typically seen as relational, even altruistic in its essence. On the other hand, individualism is characteristically anchored within ideas of competition and self-fulfilment (op cite).

In its broadest sense, individuals rather than social units are the units of the most significant importance. The possibilities for personal realisation are strengthened with the increasing recognition of the individual. However, as Fine argues with the loosening, even in some cases breakdown of existing social roles, there is the potential for insecurity, exploitation and inequality (Fine,2013). Documenting individualism within the UK and Australian social policy for older people, Fine observes and emphasises the rights and choices of the cared for the rights of the carer but do not have as many rights. Referring to the large body of work that evidences negative outcomes that caring can bring, Fine argues that carers must be understood as individuals themselves; "This entails rights and responsibilities, but also it requires the right sort of support services available outside the family. (Fine, 2013, p. 436) Rather than turning our backs on individualism, Fine asserts a more nuanced recognition of the role of individualism in care. It must be developed as a condition of recognition, one that is equally applicable to those who provide and those who depend on care.

Understanding these ideas further, care ethicists assert within neoliberal welfare regimes, consumerism is the primary means to meet needs (Tronto, 2013). The market can be understood as the necessary provider most suitable to allocate and permit choice and exercise freedom. Tronto (2013) argues that in the context of neoliberalism, these concepts have become tautological, combined into a moral and political ideology that overrides normative explanations of care casting care simply in terms of market rationality. Quoting Wendy Brown (2005), Tronto understands this market rationality as a calculus of utility, benefit, or satisfaction. Connecting these ideas with well-being, utility satisfaction was described in detail Chapter 2.7 in relation to utilitarian, hedonic well-being theorisations. The argument was presented that these ideas manifest within UK Government policy articulations resulting in the valorisation of subjective well-being and as the ultimate final measure of well-being. Therefore, clear connections can be made to broad well-being theorisations based upon individualised hedonic measures of well-being and the individualism of care presented by care ethicists as characteristic of neoliberal welfare care discourse.

Therefore, a feature of neoliberalism in the context of care of older people is that families assume the responsibility for care. The ideas of freedom and choice were examined as contained within the capabilities approach to well-being in Chapter 2.10 and here, we can see clear overlaps to an ethics of care perspective in relation to Tronto's (2013) explication of neoliberalism in relation to care. Freedom understood within neoliberalism, comes to be defined solely as the capacity to exercise choice, and choice is not the same thing as freedom (Tronto, 2013, p. 67). Tronto's caring democracy and ideas of privileged responsibility challenges personal responsibility and individualism, highlighting as well-being theorists have done inequality and oppression.

Tronto (2013) does not promote the idea of absolving personal responsibility. Instead, argues that personal responsibility becomes problematic when it becomes the only form of responsibility that is important for democracy. Personal responsibility becomes blame if you cannot care for your own family and community. This ignores the reality of inequality and historical forms of exclusion, perpetuating and entrenching inequalities; "Taking care of owns own community has a different meaning in a well-endowed gated community or suburb versus a down on its luck urban neighbourhood." (Tronto, 2013, p. 121).

Finally, Tronto (2013) claims that personal responsibility denies forms of collective responsibility for care that result in confinement within households and the private sphere, thereby limiting government support for care. The distribution of unequal care leads to socioeconomic inequality, which leads to political inequality. This political inequality contributes to a cycle of socioeconomic inequality and unequal distribution of care (Kim, 2021). Connections to carer well-being can be made here, where it is recognised that oppressed groups could be recognised as vulnerable and at-risk to harm and inequality (Wolff & De-Shalit, 2007). Recent applications of both Sevenhuijsen and Tronto's ideas relating to care and democracy have been presented by Stensöta (2020), who applies caring democracy to the Scandinavian care policy context and argues that the state provides a unique capacity to reach 'care for all' and this option is superior to market or civil society solutions in this regard (Stensöta, p, 90).

In its application, the individualism of care has been examined within the 'personalisation' programme in England. This system is now synonymous with the idea of individuals procuring services themselves through a system of direct payments and individual budgets that enable people to choose how to spend the public funds allocated to them (Yeandle et al., 2012). Marian Barnes (2011) applies feminist ethics of care to the personalisation agenda in England and argues that the concept of choice is limited to decisions about what support services to buy and suggests it is an “impoverished” view of what is necessary for a good quality of life. (Barnes, 2011, p. 160). Furthermore, Barnes (2011) argues that the dominance of the ‘citizen as consumer’ discourse in policy formulation for carers (in England) results in the competing needs and interests of carers and those they care for. As a result, the relational notion of ‘caring citizenship’ does not really emerge (Barnes et al., 2015). Considering this question further, Moffatt et al. 2012, compare the devolved four nations of the UK policy approaches of choice for public service provision for older people. The authors argue that the pursuit of the choice agenda in social policy and practice is linked to a much higher risk of increasing inequalities regarding access to welfare provision for older people (Moffatt et al., 2012).

A further contribution to insights relating to the individualism of care is provided by Ward (2015), who examines these issues concerning health policy in the UK. Since the 1990s, Ward notes that the explicit language of empowerment, participation and active citizenship was used to restructure the welfare state. Central to these notions is the idea of self-care. This has resulted in the concept of self-care becoming part of the policy solution to the ‘crisis’ of NHS funding. Accordingly, frameworks and guidance are developed and evident, exhorting citizens to take more responsibility for their health by self-management of long-term health conditions and engaging in ‘healthy living practices’. Ward argues, the construction of care as individual responsibility of the self furthers existing inequalities by obscuring the collective responsibility of the state to provide care (Ward 2015).

The individualism of care is understood to be nested within a broader discourse of active ageing. Newman and Tonkens (2011) note, “The active citizen, is invited, cajoled and sometimes coerced to take on a range of responsibilities for the self, for the care of others and the well-being of communities (Newman & Tonkens, 2011). The appeal to active citizenship is framed as promoting choice voice and empowerment (Groot et al., 2019; Lloyd et al., 2014), ideas that are encased within a consumerist lens, and within the context of care of older people. Therefore, an analysis of active ageing discourse foregrounds a study of well-being in the context of family care policy. The following section summarises the conceptual underpinnings of active ageing and how these relate to carer well-being.

3.9 ACTIVE AGEING

Originally put forward by John Row and Robert Kahn (1997), the 'active ageing' model has influenced ageing policies across Europe (Foster & Walker, 2015). The active ageing model has been the subject of intense criticism driven mainly by critical social gerontologists (Ehni, Kadi, Schermer, & Venkatapuram, 2018; Foster & Walker, 2013; Lloyd et al., 2014). Two prominent narratives are identified within the active ageing paradigm, focused on productivity and health and well-being (Moulaert & Biggs, 2012; Pfaller & Schweda, 2019). Accordingly, two evaluative and normative guiding concepts can be identified: one is being "able to lead a productive life" and the other being "free to make personal choices." (Pfaller & Schweda, 2019, p. 28). Amartya Sen (1990) argues that freedom and capability are essential to the study of well-being. Freedom, however, is absent from the discourse on active ageing. There are clear ramifications concerning theorising well-being for family carers who are understood as providing a form of unproductive (unpaid) labour but also subject to the normativity of neoliberal ideas of self-care and individual responsibility (as outlined previously).

Active ageing is the dominant discourse that reiterates ideas of economic contribution, individual responsibility, and the medicalised notion of what it means to age. This discourse is portrayed mainly as fact, rather than critiqued as oppressive and ageist, again disadvantaging older people and those that care for them (Lloyd, 2005. Cited in Higgs et al., 2018). Drawing upon Sevenhujisen's idea of a 'gender logic' within care (Sevenhuijsen, 1998, p. 131), I suggest that there is 'ageist logic' that exists within the active ageing discourse which well-being care policy is based and located within a bio-medicalised notion of older age typified by frailty and dependency. This has led to a policy discourse that valorises maximising independence and presents the need to receive care as negative and contributing to a social burden (Higgs & Hafford-Letchfield, 2018). The ramifications on carer well-being are that carers are understood as productive workers contributing to relieving the care burden. However, as described, care for many comes at a significant cost evident across all well-being domains. Therefore, social justice questions are raised concerning the extent to which family carers should be protected from the harms of care and supported to care.

The ideas of equality are assumed, and active ageing is framed as a “win-win-situation” with benefits for both individuals and society; critical gerontologists have challenged this idea as a purely ideological move serving to re-emphasise neoliberal ideology (Pfaller & Schweda, 2019). Furthermore, the emphasis on personal responsibility functions as a mere alibi for dismantling the welfare state and shifting risks and costs to the individual. Consequently, the attribution of responsibility is not accompanied by more agency (Emirbayer & Mische, 1998) and empowerment, but only by the burden of negative consequences (Pfaller & Schweda, 2019). The ideal of ‘active ageing’ rests upon assumptions of equality and freedom. As social gerontologists point out, the experience of ageing and the ability to ‘age successfully depends on class, gender and ethnicity (Ward, 2015). It depends on the extent and intensity of caring responsibilities across the life course. Moreover, calls are made for a new gender-specific research agenda that focuses on an interrelation between gender and different economic aspects of “active ageing” (Foster & Walker, 2013; Paz, Doron, & Tur-Sinai, 2018).

3.10 CRITICISMS AND CURRENT DEBATES

Critics have charged early care ethicists with claims of biological essentialism and confining discussions about care to caring relationships, forgoing the political and cultural dimension in which care is situated. For example, Elizabeth Spelman challenged early care ethicists work as confined to white heterosexual, middle-class women and noted its apparent lack of intersectional reflection. (O'neill, 1990; Spelman, 1988). Further recent charges against care ethics challenge care ethics as an issue confined to feminism. Its focus on gender missed the plurality of ways that power intersects with care (Hankivsky, 2014). More recently, care ethics is coming to terms with criticisms of parochialism and western centrism (Raghuram, 2016), privileging white western views of care obscuring non-western voices relating to care from debate. Tronto (2020) reflects on the recent charges against care ethics in recent work (Urban & Ward, 2020), speaking of the need to reflect on the central position of critical theory in care ethics and drawing upon Iris Young’s (1990) work that rather than coming up with a universal answer to injustice, the focus of attention should be on critically engaging with the injustice itself; “Uncaring care may tell us a lot about how to proceed.” (Tronto, 2020, p, 460). In this way, we need to focus on the multiple ways in which care as a socio-political construction can be seen to reproduce and reflect inequalities for carers and result in unequal caring outcomes and these inequalities and how these are experienced differently between and within countries and groups. This study contributes to these ongoing debates, drawing upon primary data evidence of carer well-being.

3.11 CONCLUSION TO CHAPTER THREE

In this review of care theory, I have traced recent critical debate and discussion relating to care theory and older age care. I have presented and detailed how care can be understood as a normative idea enshrined within gender norms and characterisations relating to neoliberal welfare regimes, broader individualism of care, and active ageing paradigms.

Based on the literature review of care theory, the following findings were identified:

- Carer well-being is theorised primarily based upon an implicit or under problematised burden and stress discourse
- The burden discourse obscures the broader normativity of care
- Carer well-being is predominantly measured through subjective scales
- There is a gap in knowledge regarding how well-being outcomes operate across and within relational contexts, including socio-political and cultural levels
- There is relatively little knowledge that captures carers' views on how care influences and affects their ability 'to be and to do' what they most value.

Woven into these discussions is an ethics of care perspective. I suggest that this approach provides a particularly useful theorisation to understand and respond to carer well-being in the context of older age care.

3.12 SUMMARY FINDINGS THEORETICAL LITERATURE REVIEW WELL-BEING AND CARE

Chapters Two and Three aimed to identify a theoretical framework for understanding well-being in the context of care. It began by connecting the philosophical roots of well-being with contemporary theorisations of well-being provided by the capabilities approach. I argue the CA provides essential insights relating to the subsequent 'practice' of counting and measuring well-being. Although, as in the case of the UK, programmes to measure well-being do not necessarily provide adequate definitions or a common basis of valuation of well-being as such, well-being definitions can be understood as tautological - defined into existence by the programme itself; "Programmes to measure well-being includes measures to do with well-being." (Jenkins, 2018, p. 4). Unpacking assumptions and normative basis of well-being theory are critical; therefore, to develop an awareness of how despite welfare programmes containing stated aims to promote carer well-being, carers experience worse outcomes than the non-caring population.

I suggest that well-being in the context of care is infused with political interpretations of what 'good' care means and underpinned by ideas concerning what can and should be within the purview of government in supporting 'good' care in a given society. Understanding the political ideology (rooted in philosophical interpretations of well-being) and societal values that shape and are shaped by how well-being formulations apply to family carers is critical in responding to the central research question.

I argue that the CA to well-being provides essential insights relating to a theorisation of carer well-being in the context of older age. This argument can be summarised in the four central claims below:

- Care is essential to well-being. It is constitutive of 'secure functioning's, and in this way, they can be understood as a type of primary good and critical for human well-being.
- Therefore, the capabilities approach begins from a social justice perspective and accounts for variation in need and inequalities.
- Understands human nature as essentially relational

- Examines sociopolitical contexts through ‘means and conversions’

In relation to care theory, I presented theorisation relating to care outlining the problems of care as a normative concept imbued with ideals concerning family, gender, and older age care – the notion of burden. I presented the ethics of care as an approach to respond to the gaps in theorising well-being in care and knowledge and provided explanatory insights. Finally, I argued for an ethics of care perspective to theorise well-being in older age care based upon the central claims:

- Provides a politically rooted and social justice informed account of carer well-being
- Begins from a relational perspective of care
- Offers alternative terms on which to theorise negative carer well-being – vulnerability and dependency
- Encourages critical exploration of the socio-political and cultural application of care – individualism of care and active ageing.

Daniel Engster (2015) stresses the commonalities between the capabilities approach and care ethics and treats both as appropriate starting points for developing a theory of disability justice. I suggest that supplementing the capabilities approach with critical elements of care ethics allows for a fine-grained analysis of carer well-being. I suggest that the combination of a capabilities approach to well-being that focuses on socio-political constructions of well-being and the ethics of care approach supports ethical framing of care in older age and provides a robust analytical framework to respond to the central research question of this study.

The figure below shows the theoretical framework based on Chapters Two and Three and the merging of ethics of care and CA.

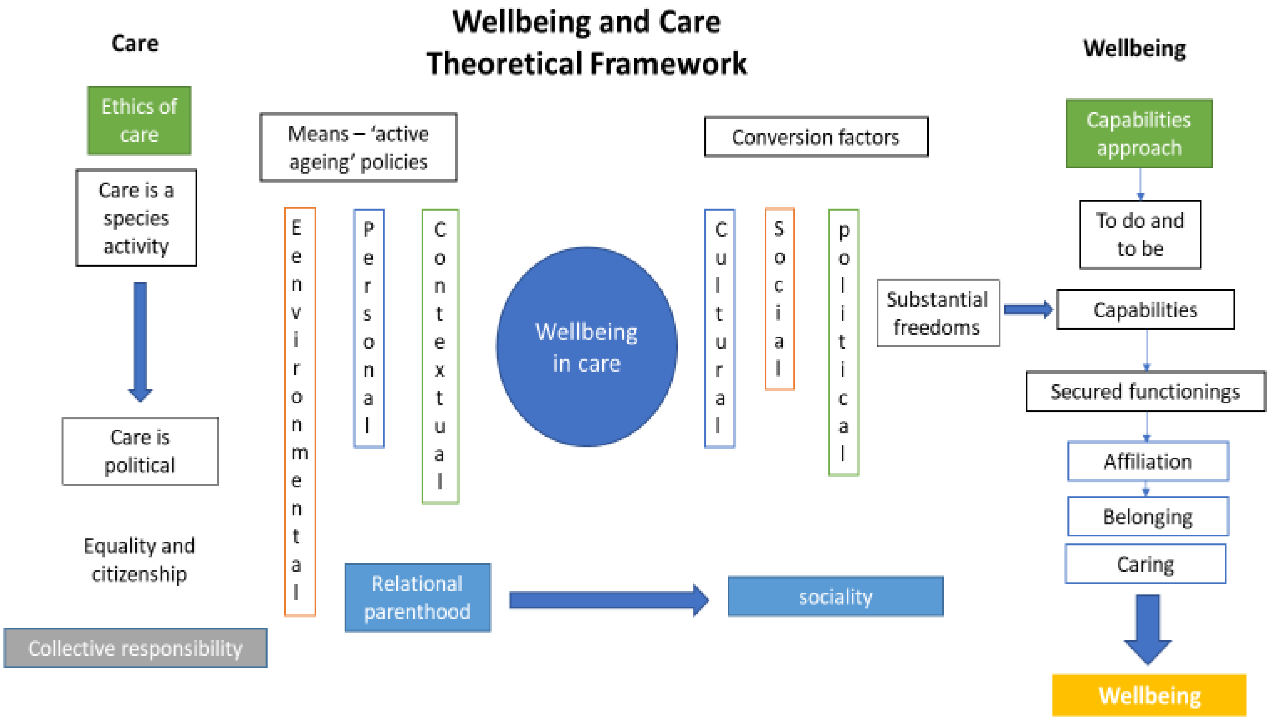

Figure 3 - Theoretical Framework

In the next section, findings are presented of a policy analysis informed by the ethics of care 'trace analysis' developed by Sevenhuijsen (2008). The analysis is applied to the Social Services and Well-being Act (Wales) 2014 and associated documents.

CHAPTER FOUR - POLICY ANALYSIS

4.1 INTRODUCTION TO CHAPTER FOUR

In the previous chapter above, I provided a review of contemporary theory concerning well-being and care. I identified the capabilities approach and critical care ethics as the most suitable theoretical frames to respond to the research question and analyse well-being phenomena within the context of older age care. CA theorists argue that a central foundation for all social policy is to expand capabilities – the space within which people can develop a conception of the good and have the opportunity and ability to live following that conception (Nussbaum, 2000, cited in Austin, 2020). This next chapter aims to deconstruct the normative framework of carer well-being embedded within key social policy texts. The analysis applies capabilities informed approach to well-being and a specific ethics of care 'trace' analysis. An overview of the structure, the method, and a narrative synthesis of the policy analysis findings follow.

4.2 STRUCTURE OF CHAPTER FOUR

The chapter responds to the research question: **1) How is well-being understood, and 3) What are the implications of this account?** This chapter is structured as follows: An introduction to well-being in social care policy is outlined. First, the history of well-being in social care policy in the UK is briefly described. Next, the well-being principle belonging to the Care Act (England) 2014 and the Social Services and Well-being Act (Wales) 2014 is presented. Next, the method of the trace analysis steps of analysis is highlighted. This section then presents a narrative synthesis of findings.

4.3 WELL-BEING IN SOCIAL CARE POLICY

Well-being discourse has become ever-more prominent, and in policy terms are often presented as a more holistic and integrative alternative to dominant orthodoxies. Within social care, well-being spans several key welfare debates. In political terms and parallel to Chaney's (2015) analysis of child care policy in the UK, carer well-being is viewed as a 'valence issue', that is, it is an issue that unites voters, few would argue against a programme of policy development that does not seek to promote carer well-being, and as Manthorpe (2019) notes; "Carers, it seems are a consensus subject, with political point-scoring mainly about which party has done more for them than others" (Manthorpe, 2019). However, achieving well-being for family carers can be viewed as a 'party position issue' subject to political-ideological divergence and politically contrasting views about how family carer well-being can and should be achieved (Chaney, 2015).

As a concept and in relation to care and ageing, well-being has featured within UK Government strategy for over two decades. In 2010, David Cameron, introduced the National Well-being programme which in effect embedded ‘well-being questions’ into the Integrated Household Survey in 2011. Well-being appeared in policy within the Law Commission Report on Adult Social Care (2012). With a focus on well-being, the reform of social care in England and Wales is due, in part, to this Report's publication. At the request of the UK Government, the Law Commission undertook an extensive project to enable the establishment of a set of key recommendations for reforming adult social care across England and Wales. Acknowledging the disparate and sometimes outdated range of legislative instruments that exist within adult social care at the time, the Report states that this has led some judges to describe it as; "exceptionally torturous", "labyrinth" and as including some of the "worst drafted" subordinate legislation ever encountered" (Law, 2011, p. 1; ONS, 2011). Subsequently, the UK Government produced the White Paper Caring For Our Future: reforming care and support - white paper and the draft Bill for social care reform 'Care and Support Bill' 2013 (England). The White Paper contains essential precepts relating to well-being and carers, providing a foundation for the Social Services and Well-being Act (Wales) 2014 and The Care Act (England) 2014.

The Law Commission report discusses the historical lack of a unifying definition of adult social care that has blighted legal and policy interpretations of adult social care. According to the report authors, well-being as a central organising principle could fill the gap where adult social care was mainly defined by what services are not provided. The Report notes that;

"The idea that a principle should confirm the importance of adult social care as a core function of the state is an interesting suggestion. As currently worded, this concept is probably too

vague to be included as a proposition of law and would be better placed in a policy document. However, an alternative approach, which would also confirm the importance of adult social care, could include a primary well-being principle in our legislation. This would establish clearly in law that the overarching principle of adult social care is to promote or contribute to the well-being of the individual." (Law, 2011, p. 20).

Based on the articulation of well-being within the Law Commission report, the concept provides for a positive definition for adult social care, responding to the hitherto lack of expression of what adult social care can and will deliver on and tackling the proliferation of legal instruments and interpretations into one single unifying principle. However, embedding a guide within legal frameworks is problematic due to the tensions between political ideologies and legal objectivity. The Report notes that law reform operates within the broader and changing context of Government policy (op cite, p,4). It goes on to recommend creating a law "that is not wedded to any particular policy and is capable of accommodating different policies and practices in the future". (op cite. P, 5).

In 2011, The Welsh Government published its strategy for reform of social care in the form of; 'Sustainable Social Services for Wales: A Framework for Action (Welsh Government, 2011). This document, alongside the Law Commission report, provides the background to the subsequent Social Services and Well-being (Wales) Bill 2014. The framework does not contain an explicit definition or account of well-being. Rather a description of well-being based on concepts of freedom from abuse and neglect. Under this section, well-being is related to rights and principles of dignity and respect; "It is a basic right that each of us should be free from exploitation, abuse and neglect. We expect that the relationships with those that use services will be based on dignity and respect." (Welsh Government, Framework for Action, 2011, p.39). It is significant that the concept of well-being features only four times in the policy text and mainly under a standalone section 'Promoting and safeguarding well-being for citizens'.

In 2014, the well-being principle in both England and Wales was defined in legislation. The SSWB Act and the Care Act 2014 defined well-being and legislated that local authorities have a general duty to promote individual well-being. The Act's were pivotal to carers legislation because it created the first-ever requirement on local authorities to assess the needs of carers regardless of their level of care. An assessment for carers was previously only provided if the carer provided a substantial amount of caring. The new rights afforded to carers through both the Care Act 2014 and the Social Services and Well-being Act 2014 were hailed by politicians and campaigning groups as a positive step towards recognising the value of unpaid care work.

4.4 THE SOCIAL CARE AND WELL-BEING POLICY CONTEXT IN WALES

In this section, I look in-depth at the policy texts of Wales, UK, where a well-being policy narrative has been elaborated and implemented since 2000 (Hamblin, 2019; Wallace, 2019). Primary legislative powers were introduced for the first time in Wales via the Government of Wales Act 2006. Later, The Wales Act 2017 gave extra powers to the National Assembly for Wales and the Welsh Government, (commonly known as the Senedd) and as permanent among the UK's constitutional arrangements. The Wales Act 2017 also signified a move from a model of conferred matters to reserved matters (similar to Scotland). This means that the Assembly is assumed as having legislative competence.

In broad terms, and since the 1990s devolution settlement, the Welsh Government has set itself a distinctive Welsh approach to policy making, characterised by its socialist and collectivist aspirations (Chaney & Sophocleous, 2021), and early indications of a polarised approach to policy making, in opposition to Westminster, can be identified in its early programme of Government. Published in 2005, 'Making the Connections' document from the Welsh Assembly set out plans to: increase citizen involvement and ensure equality of opportunity and universal access to high quality public services, via a process of collaboration and co-operation, rather than competition (Welsh Assembly Government January 2005). This can be understood as a direct challenge to the neoliberal competition driven and market led approach, preferred and implemented by Westminster government (Greer, 2016). A consistently elected labour led Government has in turn, delivered a health and social care programme that can be understood as part of a broader project to develop a distinctive approach from England. Underpinning this approach is ‘Prudent Health Care’, which articulates an approach to health and care policy making based on the key objectives of:

- Minimising avoidable harm.
- Delivering the best-evidenced treatment and services to the most appropriate level, based on individual need.
- Promoting ‘co-production’ of health and shared responsibility for delivering health care. (Aylward, Phillips, & Howson, 2013)

Amongst the devolved nations and in relation to the ‘care crisis’ Wales has also developed a distinctive strategy. In 2003, Wales was the first devolved country of the UK to create and publish its 'Strategy for Older People'. This contained the commitment to appoint an (internationally unique) independent office of the Commissioner for Older People. Despite, ‘the world firsts’ however, the Welsh population has a high percentage of people who report a poor perception of their health and a higher proportion of older people with lower levels of financial means, compared to the rest of the UK (White, 2012). Wales is a small country with a population of just over 3 million, unequally distributed and reflective of its industrial heritage, with dense regions clustered in the south and eastern valleys. Over two thirds of the population live in rural communities. Moreover, in line with other western welfare regimes, demand for social care is certain to increase associated with issues outlined in Chapter 1.4. concerning demographic and socio-political driven factors such as welfare retrenchment and social care workforce issues.

In response to these and other challenges, the Senedd’s Health, and Social Care (HSC) Committee undertook an inquiry to inform a workforce strategy for health and social care sector. The inquiry report highlights issues facing the social care workforce related to recruitment and retention across the sector. Furthermore, the report notes the high incidence of domiciliary care packages handed back to LAs, with care agencies reporting that they simply cannot recruit and retain staff (James, 2022). There are clear impacts on unpaid carers here, with many carers of this study (and reported on in Chapter 7 – Findings) without access to, or options for appropriate care support packages that would enable them to have a break and support their well-being. In December 2021, Julie Morgan, Deputy Minister for Health and Social Services announced that the WG will provide LAs and Health Boards with £43m so that they can implement the Real Living Wage from April 2022. Although a welcome improvement, many commentators note that realistically this alone will not resolve the issues and that taking a multi-faceted approach and continued commitment and funding from the WG will be required to see real improvements in the sector (James, 2022).

In response to calls for further social care reform, and with its new conferred powers, in 2018, the Welsh Government commissioned Lord Holtham to undertake a review of paying for social care. Despite increasing demand, the Holtham Report found that total spending on older adult services in Wales fell in February 2018, and noted one explanation may be a trend towards tightening local care packages (Holtham, 2018). Moreover, the decrease in spending has gone along with a reduction in capacity in the care home sector, a trend the author notes not specific to Wales (op cite). With new tax levying powers afforded to Wales through the Wales Act 2017, the Welsh Government is currently considering its response to social care reform and Professor Gerald Holtham's recommendations. Current options considered by Welsh Government include, introducing a tax or levy on incomes that could be hypothecated to social care rather than being part of a broader general revenue.

The left leaning policy rhetoric of the Labour Government in Wales can be understood to be carving a hybrid programme of social care welfare reform, one that can be understood as resistant to welfare retrenchment and broadly aligned with the collectivism advanced by care ethicists and outlined in Chapter 3.6. The central components of this distinctive path are outlined in the Welsh Government's White Paper on social care reform 'Rebalancing Care and Support' published in 2021 (Government, 2021). Contained within it, is the acknowledgement of the need to address the complexity and bureaucracy of current social care systems. Currently in Wales, social care structures are delivered through the SSWB Act and centre upon Regional Partnership Board (RPBs) structure. The RPBs are designed to promote a pluralistic approach to welfare delivery (Chaney, 2021), and include a statutory duties to co-produce well-being outcome for all, bring together key delivery partners including; local government, third sector, and health boards. Despite the policy rhetoric of co-production however, these structures have been heavily criticised for their complexity, which commentators note has undermined the transparency of the system and in turn the type of deliberative democracy the system was designed to promote (Chaney & Sophocleous, 2021)

Moreover, in response to the criticisms regarding delivery mechanisms for social care, the White Paper includes a commitment to establish a National Office to oversee a national framework for social care that would reduce complexity within sector and drive service improvement (Government, 2021). Further distinctive reforms have been announced through the Co-operation Agreement between Welsh First Minister Mark Drakeford and leader of Plaid Cymru Adam Price. This Agreement establishes a commitment to the establishment of an expert advisory group to make recommendations on how to deliver reform for social care including the establishment of a National Care Service. The Deputy Minister for Social Services Julie Morgan has confirmed that the National Care Service is essential to fulfil Welsh Government's so called 'social care promise' that is - free at the point of need and continuing as a public service (Julie Morgan, 21 February 2022). Recommendations from the expert group are expected in Summer 2022. Based on these reforms, Welsh Government strategy in relation to care exemplifies a form of collectivism, and according to care ethicists an essential precept of good care as outlined in Chapter 3.6.

The Welsh Government is steering a divergent course on care issues, distinct from Westminster. It has set itself a vast and ambitious agenda, through the promise of a National Care Service, free at the point of need and a wholly public service. The effects of Covid-19, Brexit and broader global issues, will undoubtedly however, place into question the extent to which reforms can bring about lasting positive well-being outcomes for carers. However, a package of change is clearly articulated by Welsh Government and one that is normatively consistent with the broad value base of an ethics of care and CA to well-being.

In the next section, I look in more depth at the framing of care within care policy in Wales and, drawing upon trace analysis, explore the value base and ramifications on family carers. Specifically, the analysis focuses on policy texts relating to The Social Services and Well-being (Wales) Act 2014.

The Policy texts included in the analysis were:

1. WG. Sustainable Social Services: A Framework for Action.
2. WG. Well-being statement for people who need care and support and carers who need help. 2016.
3. WG. National outcomes Framework for people who need care and support and carers who need care and support. 2016.
4. Social Services and Well-being Act (Wales) 2014.
5. Healthier Wales. Our Plan for Health and Social Care. 2018.
6. Care Act (England) 2014
7. White Paper 'Caring for Our Future'

4.5 METHOD

The method combined content and critical discourse analysis. A conceptualisation of well-being for care is applied to the policy texts, and the analysis is informed by the specific steps outlined in the 'trace' framework approach put forward by Selma Sevenhuijsen (2003). Trace analysis aims to; "Trace the normative framework (s) in policy reports to evaluate and renew these from the perspective of an ethic of care. The background motivation of this approach is the wish to develop care into a political concept further and to position care as social and moral practice in notions of citizenship." (Barnes, 2011, p. 155). Ethics of care analysis has been applied to the context of social care (Barnes, 2011; Bond-Taylor, 2017; Lloyd, 2010; Ward, Ray, & Tannner, 2020). Both Lloyd and Barnes apply the ethics of care perspective to the personalisation agenda in England, and Bond-Taylor examines the troubled families programme in England through an ethics of care lens. Ward et al. (2020) apply ethics of care analysis to social care crisis in England, drawing upon older people's experiences of social care services. No such application has been used to family care well-being policy.

Sevenhuijsen (2003) designed the 'Trace Method' to evaluate policy texts. Using this method, she interrogates the Dutch policy document' Choices in Health Care', describing the policy document as a "Vehicles of normative paradigms" (Sevenhuijsen, 1998a, p. 123). In this current discussion, the following elements of Trace analysis have been applied to the policy texts analysed in the following way:

- How it defines the problem to be addressed
- Identify the leading values at work within it
- What suppositions about human nature are contained within the text
- How care is defined and elaborated
- Whether the role of gender in caring arrangements is acknowledged

The trace analysis method was chosen because of its primary focus on identifying the normative value base upon which care policy is based. However, as Marian Barnes (2011) notes, however; "It is not a neutral endeavour. It derives from feminist scholarship that has sought to 'de-privatise' and de-gender' care, but also to expand our concept of citizenship through including care within it." (Barnes, 2011, p. 156). The critical review identified ethics of care and the trace analysis. It was considered particularly suitable as it aims to support the identification of the implied meanings of texts and documents. Combining this with the foundational ideas of well-being put forward by the capabilities approach I suggest can help identify the implicit and latent meaning of well-being concerning family care of older people.

The research question used during content analysis was *'How is well-being in relation to carers expressed?'* The critical policy texts were first analysed using the sampling unit 'well-being'. Next, the documents were scanned for text relating to this concept. Finally, sentences were highlighted and coded based on the literature on well-being and carers, and keyframes were identified. Frames are described as a collection of idea elements tied together by a unifying concept that serves to punctuate, elaborate and motivate action on a given topic" (Creed, Langstraat, & Scully, 2002; Yanow, 1999). Latter stage analysis using the ethics of care trace analysis was then applied to inform an evaluation of the impact of the policy on family carers.

4.6 THE POLICY FRAMING OF WELL-BEING AND CARE IN WALES

The trace analysis begins with how the policy texts' frame' the problem to be addressed. Population ageing is highlighted within the WG's white paper Sustainable Social Services:

A Framework for Action (WG, 2011[2]) as a critical challenge facing public services in Wales. The then Deputy Minister's foreword includes reference to these challenges: "There is a choice: retrenchment or renewal. Retrenchment would see fewer people receiving services, greater expectations that people find their solutions, increased burdens on informal carers" (WG, 2011). Here we can see that 'informal carers' are identified as a group associated with the burden of caring, with an implied intention to improve the situation of family carers. This white paper laid the groundwork for the subsequent Social Services and Well-being (Wales) Act of 2014 (SSWB), where again the descriptor of caring is associated with burden. In 2015, the WG published its well-being statement for people who need care and support and carers who need care and support:

> Everyone is entitled to well-being, and everyone has a responsibility for their own well-being, but some people need extra help to achieve this. Defining what is meant by well-being is about securing an approach based on working in partnership with people, giving people a stronger voice and greater control over their lives, and empowering people to achieve their own well-being with the appropriate level of care and support. (WG, 2015) [3]

Thus, at face value, the carers' well-being statement includes several elements of "care-full policy" (Bond-Taylor, 2017, p.133) congruent with Tronto's (2013) five principles; attentiveness, responsibility, competence, respect and caring. Yet as we work through the stages of trace analysis, complexity and ambivalence emerge. Obligations and rights are closely entwined and relate to the question of responsibility to care for sick older family members. I will now apply the ethics of care lens to explore the implications of these concepts on family care.

4.7 VALUES – OBLIGATION TO CARE

Beginning with the idea of obligation and the question of who is responsible for older family care, in some cases, this is made explicit through policy and legislation. In contrast, in other

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[2] Welsh Government. (2011). Sustainable Social Services: A Framework for Action. *Welsh Government*. http://www.wales.nhs.uk/sitesplus/documents/829/WAG%20-%20Sustainable%20Social%20Services%20for%20Wales%202011.pdf Retrieved on 14/09/2020

[3] Welsh Government (2015). Well-being statement for people who need care and support and carers who need support. Welsh Government. https://gov.wales/sites/default/files/publications/2019-05/well-being-statement-for-people-who-need-care-and-support-and-carers-who-need-support.pdf Retrieved on 14/09/2020

cases, it is something that happens "through the back door." (Kodate & Timonen, 2017). Applying a trace analysis lens to the policy texts, several values emerge 'through the back door'. The first relates to the implicit supposition that family care is the ideal and preferred means of support, evidenced with statements such as:

> For many people, the support they need will be delivered by different people – professional and unpaid carers, family and friends, community volunteers, housing organisations and neighbours, as well as themselves" (WG, 2018. A Healthier Wales: our plan for health and social care). [4]

Of the eight references made to different providers of care in the extract above, only two – 'professional carers' and 'housing organisations' – can be viewed as government-sponsored support services. The different terms used to refer to family carers – 'unpaid carer', 'family and friends, 'volunteers' – essentially take family care to be embodied in the activities of specific individuals in a contingent relation to the care receiver. In this respect, this key policy document is in stark tension with previous policy intentions to draw away from an overly reliant system on unpaid family. Rather, it confirms a reliance upon and intends to appreciate and value the unpaid family care workforce. At the same time (and as encountered above), a discourse around 'problem', 'burden' and 'drain' underlies the policy narrative for carers. This combines with a simultaneous and contradictory language that recognises the ill-effects caring can have on individuals and propagates a naturalising obligation to care for those same individuals.

For carer well-being, the condition on which carers have genuine opportunities to promote their well-being are thwarted by norms that infer the obligation and expectation to care – practices that research has repeatedly shown can have negative implications on well-being. The point of entry for an ethics of care analysis in making sense of this contradiction focuses on how the self is positioned both as interconnected and inherently obligated. On this basis, negotiating the balance between individual and collective responsibility to deliver care revolves around respecting our connectedness and allowing for individual freedom. In effect, this individualistic understanding of care positions care within the individual family unit and

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[4] Welsh Government. (2018). A Healthier Wales: our plan for health and social care. https://gov.wales/healthier-wales-long-term-plan-health-and-social-care. Retrieved on 14/09/2020

detaches it from the state. As a result, family carers have limited real freedom to choose not to care. In turn, this limits their essential capability to lead the life they choose or to achieve their well-being. This contradiction lies at the heart of the value basis through which unpaid family care is enacted.

4.8 VALUES – THE RIGHTS OF CARERS

Additional values are identified concerning enhancing the rights and entitlements of carers. Rights are tightly connected to ideas of obligation (or responsibility) stemming from the enactment of legal rights in western democracies. The first section of the WG well-being statement affords new rights and entitlements to well-being, including carers; "Everyone is entitled to well-being…." (WG, 2015). The SSWB Act and The Care Act (England) 2014[5] provided a step-change in affording carers the same rights as care receivers. In effect, this creates a legal imperative incumbent upon all public bodies to provide a carer's assessment (where requested) that aims to identify what support can be offered (heavily means-tested) to promote the carer's well-being.

Including family carers within social care reform programmes is significant and has been generally accepted by campaigning and advocacy groups in England and Wales as progressive (Yeandle et al., 2012). But implementation has been partial. Thus in 2016-17, WG data has shown that 6,207 assessments of need for support for carers were undertaken, leading to the provision of 1,823 support plans for carers (Stats Wales, 2016-2017)[6]. By these figures, at that stage, 3.5% of self-reported carers in Wales had received a Carers Needs assessment. The substantially low numbers of needs assessments reported by Government statistics have led to a cross-party inquiry into the impact of the SSWB Act on Carers.

Making sense of this complexity, Sevenhuijsen (1998) argues it is through invoking the language of equal rights that policymakers evade the political and philosophical complexities

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[5] The Care Act (England). 2014. https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted Retrieved on 14/09/2020

[6] Stats Wales. (2016-2017). Adults assessed and measure. https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Adult-Services/Service-Provision/adultsassessed-by-localauthority-measure Retrieved on 14/09/2020

of determining 'necessary care' and thereby resorting to a more "familiar ground of equal rights" (Sevenhuijsen, 1998, p, 128). The SSWB Act can also be understood as 'familiar ground' whereby carers have a right to equality of treatment to the person cared for. Still, these individual rights do little to challenge the normative premise that care is individualised and located within the private (family) sphere. An implicit language of individualism results in family care being positioned as the preferred, presumed and 'natural' solution to 'the problem of care' (Barnes, 2011). This narrative forecloses any discussion of the deep complexity and balancing of rights obligations, freedoms and everyday moralising that takes place 'within care'.

Furthermore, matters of rights and justice are usually positioned quite separately from questions of resource allocation (Lloyd, 2010). As we can see in this instance, the promotion of rights and entitlements have not readily converted into support services to support carers' well-being. An ethics of care analysis can help make sense of the apparent contradiction whereby, on the one hand, unpaid carers are afforded more rights, and their role is increasingly recognised. On the other hand, they are relied upon ever more heavily. As shall be argued in the following sections, increased rights at the formal level do not easily convert into the kind of exercise of real freedom taken as central to well-being – due, I suggest, to implicit assumptions concerning human nature, of an individualistic, atomistic and 'responsibilising' kind.

4.9 VALUES – RESPONSIBILITY AND SELF-CARE

The third value evident within WG's characterisation of well-being within care is responsibility, exemplified through the Outcomes Framework of the SSWB Act: "Care and support will be based on the well-being outcomes that people want to achieve, and on their rights and their responsibilities" (WG, 2019)[7]. An ethics of care approach highlights key assumptions concerning human nature. We can see that the WG's association of 'carer' and 'well-being' with the value of responsibility is foregrounded by assumptions about human

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[7] Welsh Government. (2019). The national outcomes framework for people who need care and support and carers who need support. https://gov.wales/sites/default/files/publications/2019-05/the-national-outcomes-framework-for-people-who-need-care-and-support-and-carers-who-need-support.pdf Retrieved on 14/09/2020

nature discursively nested within the concept of 'active ageing and active citizenship'. This was discussed in detail in Chapter 3.8. The WG well-being policy texts specifically refer to active ageing as evidenced by the following: "People have a responsibility to do the things that keep them healthy and active. There are five lifestyle behaviours most commonly attributed to good health" (WG, 2019). Verhoeven and Tonkens (2013), in their comparison of 'active citizenship' in the Netherlands and England, argue that the promotion of active citizenship in the two countries serves as a justification both for individuals shouldering responsibility for tasks formerly performed by the state, such as providing care, and for them taking responsibility for their health and well-being. Thus promoting 'active citizenship' has become the 'ethical a priori' of neoliberal policy-making in Western welfare states (Verhoeven & Tonkens, 2013).

An associated outcome measure of the well-being statement for WG is the number of people who have two or more healthy lifestyle behaviours – a key measure to be reported in the annual well-being report. The idea of self-care was discussed in Section 3.8, where it was argued that self-care could be understood as a manifestation of the neoliberal ideology of individualism in care. Concerning family carers, the policy discourse of active citizenship and self-care points to an ethical narrative that can be seen to justify reliance upon family care within the pursuit of welfare state reform. As outlined previously, evidence shows that caring can come at a high cost for some people. The advocation of healthy lifestyle behaviours for carers is complex concerning the associated, well-documented adverse effects of caring on health and well-being.

The concept of family carer well-being predicated upon responsibility leads to a triple burden for family carers: a responsibility to do things that keep themselves healthy and active, to prioritise the person they are caring for, and also (increasingly, in the UK) to remain in employment (Pickard, 2019). The question arises: should family carers in the context of increasing dependency, low levels of welfare support and increased female labour market participation be subject to the ideological imperatives of responsibility and active, healthy ageing? In effect, this places a triple obligation on family carers, 'responsibilised' regarding their health and well-being, that of the person they are caring for, but also their ongoing attachment to the paid labour market.

4.10 VALUES - INDEPENDENCE

Independence is the defining feature of carer well-being, reflected in the following statement; "Carers make a vital contribution to promoting the well-being and independence of the people they care for" (WG, 2014). Independence lies at the very basis of the SSWB Act. Section 3 describes the Act's general duties: "All persons exercising functions under this duty must have due regard to the importance of promoting the adult's independence wherever possible" (SSWA Act, 2014: p, 7). The assumptions and norms operating in the language of independence have important implications for family carers and are problematic in an ethic of care. From this perspective, fundamental to what makes care an essential facet of life is the extent to which human life is defined by dependence, placing relationality at its core (Sevenhuijsen, 1998a; Sevenhuijsen, 2003; Tronto, 1993; Williams, 2018). Sevenhuijsen (2003) writes that an ethic of care offers a critical perspective on the norm of independent citizenship, highlighting the false dichotomy created between autonomy and dependence, individual and community, independent citizens and those dependent on care (Sevenhuijsen, 2003, p. 183). In the policy texts considered here, dependence is explicitly devalued in favour of independence. Lloyd (2010) points to the assumption that placing care alongside the assumed value of independence ignores the extent to which, for many older people, care needs are intensified and related to circumstances of dying – and so care must necessarily encompass more than the restoration of independence (Lloyd, 2010).

It follows then that if dependence is regarded negatively, then care is devalued – and that carers themselves are also devalued (Tronto, 1993, p. 141). This is because caring takes place within a complexity of relationships. Yet, particular stress on the value of independence is peppered throughout social policy in the UK. This has profound implications for the well-being of carers where they cannot access the support and services they require *due* in part to the prioritisation of independence as the ideal ambition for all social care support. In these ways, the enduring and extensive influence of the value of independence in framing policy objectives runs counter to an ethics of care perspective. This narrative directs attention away from a conceptualisation of care that recognises the inevitability of human dependency and vulnerability, which was highlighted in Chapter 3.7 as essential to understanding carer well-being (Engster, 2019).

4.11 TRACE ANALYSIS – GENDER

An ethics of care approach emphasises the gendered nature of caregiving. In the case of WG policy, we can see that the language of the 'Framework for Action' signals an intention for radical change and places importance on the idea of a distinctive welfare reformation agenda for Wales: "We are not prepared to see a return to the days in which support relied disproportionately on the family (very often on women) or where the answer was large scale institutional care" (WG, 2011). This statement represents the *single* occurrence across all the policy texts analysed of explicit recognition of the disproportionate number of women who carry out most unpaid family care. Otherwise, family care is presented as gender blind within the policy texts analysed. Barnes (2011) observes a similar finding in her analysis of personalisation in England, noting that "the image of the independent choice maker, summoned by PPF embodies masculine 'virtues' in contrast with the feminised, dependent welfare subject" (Barnes, 2011, p. 158).

Furthermore, the apparent 'gender blindness' of well-being in care policy runs contrary to the WG's self-stated ambition to become a feminist government. On International Women's Day in 2018, Carwyn Jones, former First Minister for Wales, announced that Wales would strive to be a feminist government, placing gender equality central to all of its' policy-making and strategy and attempting to follow what the Swedish Government had achieved in 2014 - the world's first "feminist government". However, the policy texts analysed do not suggest any indications of recognising the gendered nature of care. This may signify and reinforce a lack of attention to the gendered aspects of the 'crisis' in caregiving (Moen & DePasquale, 2017).

4.12 CONCLUSION TO CHAPTER FOUR

On a superficial content analysis, WG well-being discourse would suggest a policy narrative that may seem broadly in keeping with the principles of an ethics of care approach. However, through the deeper-probing lens of trace analysis, we find that references to family carers in

WG policy are framed in the assumed value of responsibility and independence, both of which are positively valorised. This pattern reinforces the masculinised model of the independent choice-making subject and positions the role of the family carer as the default and optimal solution to the 'problem of care' (Barnes, 2011).

For the purposes of this analysis, I have bracketed the question of whether these implications of the policy are directly intended or are more accurately seen as side effects of dominant neoliberal modes of discourse. In their recent study of health policy in the UK, Oliver et al. (2019) identify several factors that can give rise to unintended effects on targeted population groups, including underlying models and theories of policies that are not always made explicit (Oliver, Lorenc, Tinkler, & Bonell, 2019). From this perspective, there is a tension between the policy intended to promote carers' rights on the one hand, and on the other, a set of implications that either neglect or positively undermine the real freedom of carers to choose *not* to care. Can policy *avoid* such adverse unintended outcomes? I argue that it can be part and parcel of evidence-informed policy decision-making. It considers the kinds of side-effects highlighted and minimises the chance of unintended adverse outcomes (Oliver et al., 2019).

Further, the findings here challenge current suggestions (Pickard, 2019) that policy directives should be directed towards 'replacement care' for family carers. Instead, I suggest that governments focus on providing carer support services that furnish genuine opportunities on the part of family carers to achieve individual well-being, recognising that the labour associated with caregiving and care receiving is essential to living a fulfilled human life. This involves identifying that acts of caring are not reducible to a simple exchange of tasks or transactions but are more complex in ontological and normative terms. For the family carer, doing justice to these insights would involve dimensions of support that move beyond the limitations of individualised discourses of responsibility and independence while also acknowledging the crucial economic contributions made by informal care: for example, an increase in the opportunity for respite care, and the provision of support services that work around the carer as well as the care receiver.

4.12 SUMMARY OF FINDINGS: CHAPTERS ONE, TWO AND THREE

So far, I have presented findings based on a critical review of the theoretical literature relating to well-being and care in the context of older age and a policy review of the Social Services and Well-being Act (Wales) 2014 and associated documents. The findings informed the analytical framework shown below:

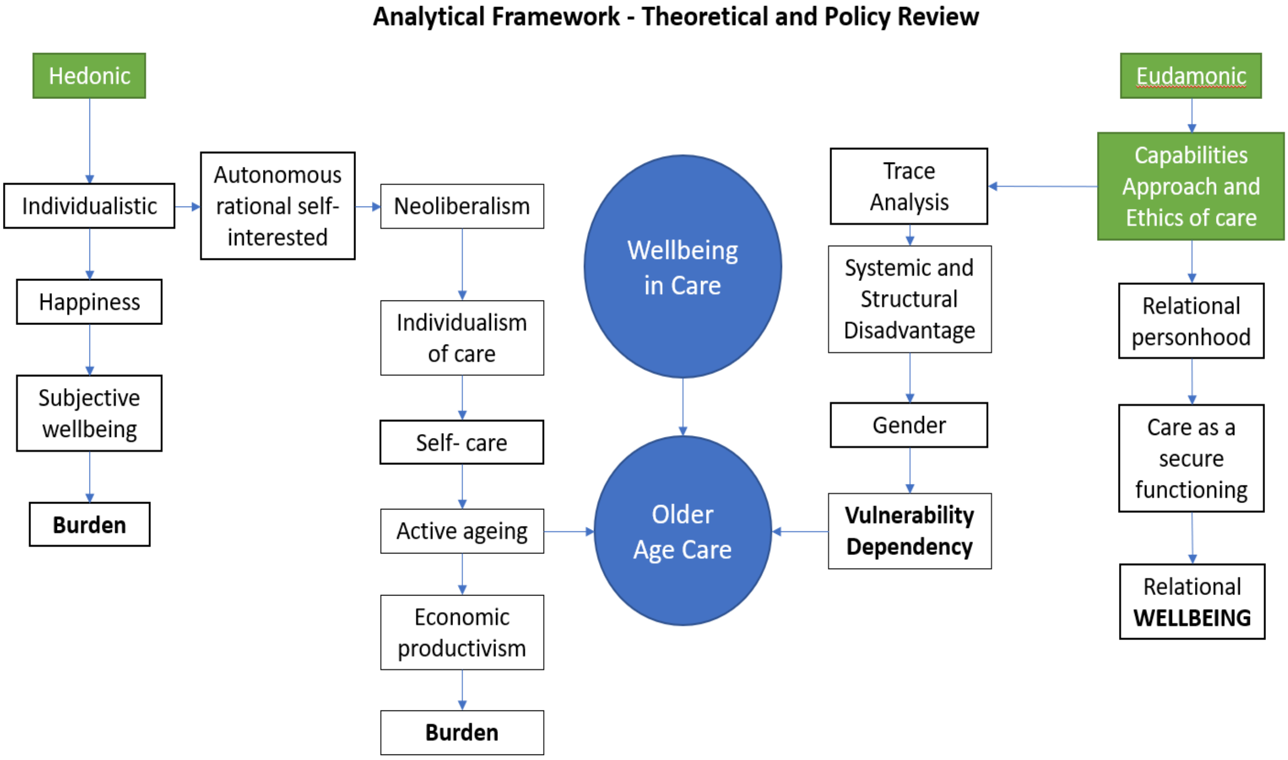


Figure 4 - Analytical Framework Theory and Policy

The forthcoming section **Scoping Review: Chapter Five** presents results from a scoping review of the empirical literature on the impacts of care on carer well-being.

CHAPTER FIVE – SCOPING REVIEW EMPIRICAL IMPACTS OF CARE ON WELL-BEING

5.1 INTRODUCTION TO CHAPTER FIVE

The previous section presented findings from a review of the conceptual developments and major well-being constructs concerning care. In summary, the conceptual research on well-being within care lacks a specific focus on older age care. Furthermore, it is dominated by psychological, subjective theoretical accounts framed through the construct of burden and stress. To inform the development of an understanding of well-being in the context of care, specific theoretical approaches have been selected that align with the study overall aims. I identified two critical theoretical approaches; ethics of care and the capabilities approach to well-being. I argued that this theoretical approach supports the explanation and examination of well-being in the context of family care. In this current section, findings are provided of a scoping review of the empirical literature relating to the outcomes on care on family carer well-being. The review aims to analyse the consequences of family care to create a knowledge synthesis of the literature. This knowledge synthesis is used to hypothesise specific properties of well-being that are of significance to family carers of older people.

Several knowledge syntheses do exist that attempt to bring together the heterogeneous and interdisciplinary research on the consequences of family care, and these have made substantial contributions to understanding the predictors, factors, influences and outcomes of family care (Bauer & Sousa-poza, 2015; Pinquart & Sorensen, 2003; Pinquart & Sörensen, 2011). This large body of work has been generally developed from the viewpoint that family care is burdensome and impacts negatively on caregivers, and has demonstrated consequences within several domains, including on carers health (Collins & Kishita, 2020; Pinquart & Sörensen, 2004b; Pinquart & Sörensen, 2003), wealth, (Keating & Eales, 2017b; Keating et al., 2014) social networks (Keating and Eales, 2017) and on working carers employment status and experience (Lai & Leonenko, 2007). With some exceptions (Jones, Winslow, Lee, Burns, & Zhang, 2011; Ratcliffe, Lester, Couzner, & Crotty, 2013; Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015), most studies aim to enhance understanding of the triggers for burden and identify interventions that could mitigate negative impact. However, there has been no systematic review that attempts to align the empirical outcomes of family care with well-being constructs. Given the continuing trend and use of the term well-being in UK policy discourse, this presents a significant knowledge gap.

5.2 METHOD

A scoping review was conducted of 45 identified peer-reviewed research articles. A thematic analysis informed by a theoretical framework developed in previous sections and based upon an ethics of care and capabilities approach to well-being was applied. The empirical outcomes of care are mapped onto the three main domains of well-being identified in contemporary well-being theory, and subthemes are identified to determine indicative well-being indicators for older family carers. In the following sections, I outline the specific steps taken, the search strategy and analysis and present the results organised under the three domains of well-being material, relational and subjective.

This review was informed by the foundational critical realist approach of this study and designed to determine the empirical and observed reality relating to family carer well-being. It addressed **RQ1; How is well-being understood in the context of family care of older people?** And **RQ2. Which attributes or properties of well-being are significant to family carer well-being?** The scoping review is a systematic literature review that aims to map the key concepts underpinning a research area and the main sources and types of evidence available (Arksey & O'Malley, 2005). The scoping review was selected because of the lack of a precise definition of well-being concerning family care and the large body of complex and heterogeneous literature (Peters et al., 2015). It is understood to support clarification of complex concepts and help to refine subsequent research inquiries. Given the lack of a precise conceptual definition of well-being in scholarly and policy fields, the scoping review characterised by its' use of broad research questions was deemed particularly appropriate. In contrast with other types of systematic reviews, it is essential to note that breadth rather than depth is the primary goal of scoping reviews (Tricco et al., 2016). The six-stage process for scoping reviews set out by (Arksey & O'Malley, 2005) and refined by (Levac, Colquhoun, & O'Brien, 2010) was adopted and is as follows: 1) identifying the research question 2) identifying relevant studies, 3) study selection 4) charting the data 5) collating summarising and reporting the results and 6) consultation on the results. As the primary aim of the scoping review is to determine broad themes and parameters a descriptive overview, quality appraisal was not conducted on the included studies. A critique of the literature is therefore not provided in the discussion on findings.

5.2.1 Search Strategy

The central research question informed a search strategy that was developed and guided search terms. Four key areas were identified and used: family care, older people, well-being and outcome and these key areas were explored for suitable synonyms and related words. To ensure focus on family carers, the use of the adjacent three functions in the search engines, that is, the word family and its variants, was within three words of the word carer (Keating et al., 2017). 'Outcomes' were confined to the broad conceptualisation of well-being put forward by McGregor and Pouw (2016) identified through the first stage critical review. These are material, relational and subjective (McGregor & Pouw, 2016; Sen, 2017). Synonyms of outcomes were used 'consequences, effects etc.' It was determined that outcomes based on interventions would be excluded from the review at the initial stages because of study focus on the construction of conceptual characteristics rather than practice-based interventions. Furthermore, drawing from similar a review (Cunningham and Cunningham, 2019), it was decided that 'quality of life' would *not* be included as a synonym of well-being because it was considered lacking in definition and may have the potential to distort focus and results (Cunningham et al., 2018).

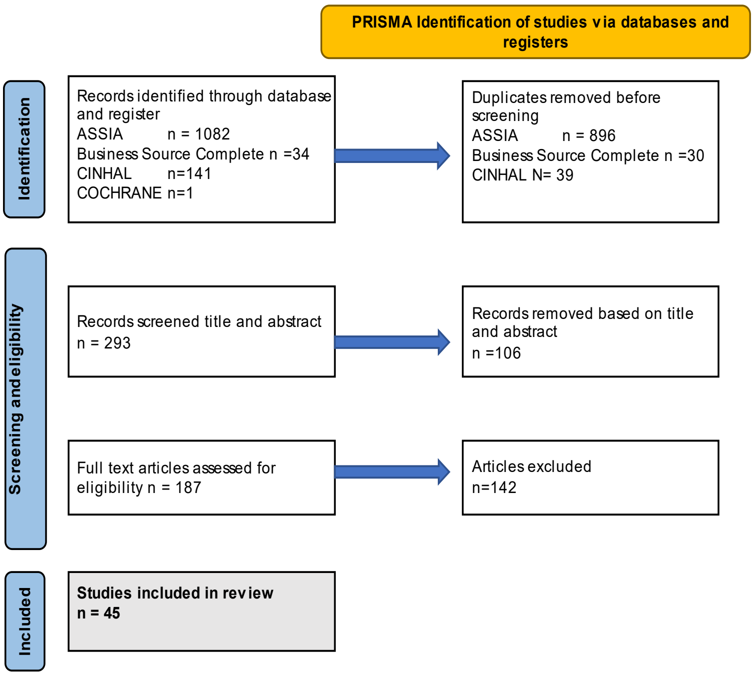
Post-hoc inclusion and exclusion criteria were applied. The time scale for the study was ten years 2010-2020, restricted to peer review articles and English language only. Three databases were screened; ASSIA, Business Source Complete and CINHAL. In addition, the Cochrane Database of Systematic Reviews were searched.

Table 2 - Scoping Review search terms used

(TITLE-ABS-KEY (famil OR relative* OR informal* OR non-professional OR non-professional OR spouse* OR sibling* OR son* OR daughter* OR husband OR wife* OR partner* OR filial OR friend* OR kin* OR (non-kin AND w/n 3 carer OR caregiv* OR "care giv*") OR supporter)) AND ((TITLE-ABS-KEY ("age* 65" OR frail OR frailty OR elderly OR elders OR pensioner* OR "ageing population" OR seniors OR geriatric* OR gerontolog* OR "old* people")) OR (TITLE-ABS-KEY ("old* person*" OR "old* adult*" OR "old* individuals" OR "senior* people" OR "senior* person*" OR "senior* adult*" OR "senior* individuals" OR retire*))) AND ((TITLE-ABS-KEY (outcom* OR experience* OR consequenc* OR situation* OR process* OR "lived experience*" OR "every day liv*" OR "life experience*" OR realit* OR change* OR poverty OR cost* OR income*)) OR (TITLE-ABS-KEY (finance* OR money OR wealth OR "mental illness*" OR "mental ill health" OR "mental ill-health" OR loneliness* OR well-being OR well-being OR isolation OR contact* OR network*)) OR (TITLE-ABS-KEY (friend* OR social* OR "marital difficult*" OR "family difficult*" OR "self identity" OR self-identity OR health OR health OR illness* OR sick* OR enhancin* OR advancing* OR positive*)))

5.2.2 Inclusion and Exclusion Criteria

The search strategy involved screening titles and abstracts reviewing the full article review. Based on the three database searches, 821 titles and abstracts were screened. After an initial assessment of the articles, it was apparent that the search had returned irrelevant studies, so criteria for inclusion and exclusion were revised based on the initial screening and trialling of the search strategy. Additional exclusions applied were: 1) about formal or professional carers; 2) opinion-based articles, commentaries or editorials, 3) not available online 4) the lived experience of the cared-for person 5) that were based on interventions 6) that were about carers' perspectives on care receivers. These exclusions were carefully considered and helped to reduce the likelihood of generating an unmanageable large number of references. Forty-five articles were left for full-text review. Fig 4 below presents PRISMA diagram.



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71doi: 10.1136/bmj.n71

Figure 4 - PRISMA Scoping Review

5.2.3 Data charting and Extraction

During coding and identifying the well-being outcomes of care on family carers well-being, the question of 'outcome of what?' was deliberated. This refers to whether the outcome is a domain of well-being in itself or is, in fact, a causal or constitutive feature of well-being. For example, the Aristolean account of well-being understands that human beings are constituted by their activity in social and political spheres. Therefore, well-being outcomes such as good physical health are measured as related and constitutive of social and political life activity. In contrast, the Epicurian account is characterised by an understanding of well-being reduced and measured solely through the dimension of pain avoidance and pleasure maximisation. This critical distinction has profound ramifications on what we understand well-being to mean and how well-being outcomes are identified and defined in the context of the scoping review. Responding to this, critical information was extracted from each article and charted using a six-stage analytical process devised by Braun and Clarke (2006).

The analysis used a combination of deductive and inductive data charting processes and took the form of a non-linear process moving back and forth from the empirical outcomes literature and the established philosophical debates concerning the broader theoretical questions of what constitutes well-being. In addition, bibliographic details, theoretical view, study methodology, design and sample, and outcome were collected (Werner, 2012).

5.2.4 Collating, Summarising and Reporting Results

A report of the review results and a narrative synthesis is provided below. The broad domains of well-being denoted as material, subjective, and relational were used to 'hold' the results and identify specific well-being properties or features salient to older people's family carers.

5.3 SUBJECTIVE WELL-BEING AND CARE

Consistent with previous reviews (Bauer & Sousa-poza, 2015), most reviewed papers focus on the consequences of care belonging to the subjective well-being dimension. Hence, it is the most frequently referred to as the consequence of care in the literature. However, as outlined previously, knowledge regarding the precise nature of carer subjective well-being is not well advanced (Chappell & Reid, 2002; Honda, Iwasaki, & Honda, 2017). Most studies polarise the concept into two distinct camp; positive and negative subjective well-being. Meta-analyses and other systematic reviews typically conclude that caregivers are more likely to experience depressive symptoms and have poorer mental subjective health outcomes when compared with various samples of non-caregivers (Pinquart & Sorensen, 2003; Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlan, 2003). However, studies show that positive and negative subjective well-being measures can co-occur (Carmel, Raveis, O'Rourke, & Tovel, 2017; Jones et al., 2011), and these studies have reported that individuals who report burden (negative subjective well-being, e.g. depression) simultaneously experience adequate levels of subjective well-being using measures such as positive affect and life satisfaction (Honda, Iwasaki, & Honda, 2017).

The positive effects reported upon can be understood broadly as belonging to the hedonic aspects of well-being outlined in the previous section. Therefore, the question of defining carer subjective well-being is complex, further compounded by the related question concerning the relationship between negative and positive attributes of subjective well-being. Therefore, the distinction between negative and positive carer subjective well-being is a site of contention and complexity. Moreover, as described previously in theory of well-being, it results in incomplete accounts of well-being, particularly in its policy applications (Bache & Scott, 2018a).

Despite the co-occurrence of positive and negative outcomes, a broad unifying feature of the reported studies concerning subjective well-being is that findings demonstrate that caregiving is stressful and can lead to an increased risk of depression and other negative subjective mental health states. For example, Pinquart and Sorenson (2004) conducted a meta-analysis of 60 studies and examined the associations between low psychological well-being (depression) with high subjective well-being (positive affect) amongst carers. The study emphasises subjective well-being as a new outcome variable in its own right and found a significant negative correlation between depression and subjective well-being, and levels of caregivers' subjective well-being were weakly related to care receivers' physical impairment, cognitive impairment and behaviour problems (Pinquart & Sörensen, 2004a).

Depression, stress, anxiety, anger and guilt are the most frequently referred to consequences on subjective well-being and burden is most frequently associated with depressive symptoms and anxiety (Bauer & Sousa-poza, 2015). Pearlin et al. (1990) developed a model that the empirical studies in this review have frequently used to explain the concept of burden amongst caregivers. Based on this model, objective caregiver stressors (care recipient needs) and subjective stressors (such as burden) affect the caregiver subjective well-being. An extensive meta-review by Pinquart and Sorenson (2003) examined the psychological effects of caring for an older person and integrated findings from 84 articles on differences between caregivers and non-caregivers in perceived stress, depression, general subjective well-being, physical health, and self-efficacy. The most significant differences were found concerning depression, stress, self-efficacy and general subjective well-being. In addition, significant differences were found between dementia caregivers and non-caregivers than between heterogeneous samples of caregivers and non-caregivers (Pinquart & Sorensen, 2003). This finding amplifies the need to appreciate the caregiving context, including the care receivers condition when anticipating or attempting to understand carer consequence on subjective well-being measures.

Amongst the studies examined in this review, the subjective burden has been primarily framed concerning anxiety, anger and guilt. A study by Del-Pino-Casado et al. (2014) aimed to understand the concept of subjective burden and its association with caregiver anxiety and anger. The authors used the Spanish version of the Caregiver Strain Index (CSI) and analysed survey data from 111 carers living in Spain. The study found that around 40 per cent of the carers reach moderate-severe trait anger levels, and about 41 per cent show moderate-severe levels of anger expressions (Del-Pino-Casado, Pérez-Cruz, & Frías-Osuna, 2014). A further study by Crespo et al. (2014) on the differences between family carers showed that spousal carers did not show higher anger or higher anger expression than childcarers (Crespo & Fernandez-Lansac, 2014). In further studies, burden has also been associated with guilt; De La Cuesta-Benjmea (2010) conducted a qualitative analysis of twenty-two female primary caregivers of relatives in Spain with advanced dementia who participated in semi-structured interviews. The women interviewed showed a reluctance to access respite services despite reporting burden, and findings showed that guilt was cited as the main reason given for non-access of services (De la Cuesta-Benjumea, 2010)

A recent study by Gallego-Alberto (2020) carried out a qualitative analysis of the narratives of 13 family caregivers of people with dementia about their feelings of guilt. Seven categories for understanding guilt in caregiving were obtained: guilt derived from actions themselves; guilt derived from one's limitations; guilt for feeling negative emotions; guilt associated with the change in the relationship with the person cared for; guilt for neglecting other areas; guilt induced by the person cared for, and guilt induced by others. The results showed cases in which guilt is absent by distress-avoiding processes. The authors conclude that guilt is a relevant variable in understanding caregiver distress, and its analysis is necessary for therapeutic work in the field of care. (Gallego-Alberto et al., 2020)

The articles reviewed also show an established link between caregiver mental or subjective stress and poorer physical health. Vitaliano et al. (2003) provide a theoretical model that relates caregiver stressors to illness and accounts for moderating roles for vulnerabilities and resources and mediating roles for psychosocial distress and health behaviours. Based on the meta-analysis of 23 studies, the physical health of caregivers of people with dementia was compared with demographically similar non-caregivers. When examined across 11 health categories, caregivers of people living with dementia exhibited a slightly greater risk for health problems than the non-caregiver sample. Stronger relationships occurred with stress hormones and antibodies. The authors conclude that caring for a family member with dementia is regarded as a chronically stressful process, with potentially negative physical health consequences. They suggest that caregiver stress may lead to poor health habits (e.g., substance abuse, poor diet), leading to physiological responses, higher stress hormones, and metabolic disorders (Vitaliano et al., 2003).

A recent study based upon data in Wales is provided by Tseliou et al., who analysed data from the HealthWise Wales (HWW) caregiver cohort to examine the impact of caregiving on the mental health of carers. Based on the cohort of 3682 carers, findings show that compared with non-carers, carers were 1·3 times more likely to indicate a common mental health disorder (Tseliou et al., 2019). In addition, a recent scoping study carried out by O-Dwyer et al. (2021) found a high suicide risk associated with caregivers with long term illnesses and disabilities. The authors note mounting evidence that highlights caregivers as particularly at risk of suicidal thoughts and behaviours but that the evidence has not been synthesised to date. Drawing upon 48 studies, the scoping study reports a paucity of evidence relating to caregivers and suicide. However, there was sufficient evidence based on the review findings to warrant concern for caregivers and prompt action in policy and service. (O'Dwyer et al., 2021).

5.3.1 Sleep

Sleep problems of carers, particularly carers of people with dementia, have been related to the negative psychological impact of caregiving. Gibson and colleagues (2015) investigated relationships between caregiving and subjective sleep reports among 434 carers (177 home-based) and 1747 non-carers (aged 55–72 years) in New Zealand. Sleep outcomes (feeling worn out, tired, or dissatisfied with sleep or having a diagnosed sleep disorder) were explored by caregiving status. Results show that home-based carers were more likely to report feeling tired some/all of the time than non-carers, and being Māori, a woman, younger or more socioeconomically deprived were also significant independent predictors of poor sleep outcomes (Gibson, Gander, Alpass, & Stephens, 2015). Honda et al. (2017) assessed the subjective well-being of 105 working family caregivers in Japan. They investigated if the association mediates the well-being of caregivers between behavioural and psychological symptoms in elderly relatives and the quality of sleep experienced by caregivers. The authors acknowledge that the concept of well-being has given rise to blurred and overly broad definitions and thus defined well-being based on subjective measures by the following three health-related items: 1) self-rated health (good vs intermediate, poor); 2) satisfaction in daily life (satisfied vs intermediate, unsatisfied) and 3) mental health condition (absence vs presence of psychological distress). The study found a significant association between quality of sleep and the proportion of caregivers with high well-being (Honda et al., 2017).

5.3.2 Positive Affect - Happiness and Life Satisfaction

The idea that caring can be a rewarding, enabling, and positive experience that results in positive effects on subjective well-being outcomes amongst caregivers is articulated amongst a number of the studies identified in this review, and mainly relating to life satisfaction and happiness measures; these measures are conceptually derived within the hedonic well-being tradition. For example, in their study of psychological well-being and depression, Sorenson and Pinquart (2004) found measures assessing positive subjective well-being affect included positive affect scales, life-satisfaction scales and perceived quality of life. However, it is noted that, unlike burden scales, positive subjective well-being measures do not have a common overarching theoretical foundation. This is a crucial point to note and identified as a knowledge gap amongst the literature and one that this study aims to respond to. Jones et al. (2011) attend to the lack of theoretical frameworks for assessing positive subjective well-being amongst carers and develop the Care-giver Empowerment Model (CEM) to explain and predict positive outcomes of family caregiving (Jones et al., 2011). However, it is unclear if the model has received empirical validation and, therefore, difficult to assess its applicability to large scale data sets, etc.

Despite the lack of theoretical underpinning, positive effects on carers have been evidenced relevant to subjective well-being in several studies. Sanchez-Izquierdo et al. (2015) surveyed 140 family caregivers of dependent elderly participated. Those caregivers who perceived sound quality of relationship with the cared-for presented more satisfaction than the others. Problems in quality of life showed a positive relationship with the level of dependence of the elder. On the other hand, the more level of dependence of the elder, the greater the level of satisfaction of the caregiver (Sánchez-Izquierdo et al., 2015). Greenwood and Smith (2015) synthesised 18 studies concerning carers' experiences aged 75 and over. They found several qualitative studies that drew attention to the rewards and praise from others for taking on the caring role, which they found was particularly important for male caregivers in navigating the caring role within the social constructs of masculinity (Greenwood & Smith, 2015).

Al Janabi (2010) provides further detail concerning caring on subjective well-being. The study adapted the Caregiver Strain Index (CSI), a commonly used outcome measure for carers and incorporated five positive items: feeling appreciated, time to self, handling care fine, happy to care, care is important. Results found that female carers were slightly less likely than males to be happy to care and less likely to feel appreciated. This work also points to positive aspects of caring not attended to within the other reviews examined, particularly concerning feeling appreciated and happy and that 'care is valued' represent a separate dimension relevant to carers not reflected in burden measures (Al-Janabi, Flynn, & Coast, 2011).

Two studies reviewed contradict previous findings on life satisfaction amongst positive aspects of subjective well-being. Hammond et al. (2015) used data from 4,096 carers living in Australia who completed the Personal Well-being Index (PWI) and Depression and Stress Scales. In this study, the authors found that of the seven life domains assessed, the discrepancy between carers and the normative population was most evident for satisfaction with achievement in life and concluded that this specific domain of subjective well-being suffers as a result of caring (Hammond, Weinberg, & Cummins, 2014). Similarly, van den Berg et al. (2014) use a sample of 23,285 carers from cross-sectional data taken from HILDA to find that providing care correlates with subjective well-being losses assessed by self-rated life satisfaction measures. However, the authors note the complexity of measuring life satisfaction amongst carers and that life satisfaction measures do not allow distinctions between positive and negative effects on caregiving with the same individual. They argue that future research could consider measuring overall well-being using measures of impact containing positive and negative subjective dimensions and that this is crucial to inform policy. The authors point out that if subjective well-being measures are not comprehensive other measures such as loss of income and morbidity impacts must not be ignored (van den Berg, Fiebig, & Hall, 2014).

Care as a meaningful life-affirming, and positive aspect of one's life can be understood as a type of eudaimonic understanding of well-being and was discussed in well-being theorisation in Chapter 2.6. Several studies point to eudaimonic aspects of well-being; in one study of Christian caregivers by Shim et al. (2013) found caregivers expressed caregiving as an opportunity for growth and transcendence. Furthermore, caregivers found meaning by believing in a choice of attitude and perceiving satisfaction in living according to their values in life (Shim, Barroso, Gilliss, & Davis, 2013). Similarly, results from Grant et al. (2012) on carers of people with COPD found that caring can also be a source of personal satisfaction with the relationship with the cared-for person, and the meaning attached to caring are critical concepts in this satisfaction (Grant, Cavanagh, & Yorke, 2012).

A more recent scoping review was conducted by Pysklywec et al. (2020) to understand the nature of the most contemporary literature regarding the positive effects of caring for carers of adults aged 65 or older. The central finding of the review was that the positive effects of caring are relational and were linked to the carer through distinct relationships. These relationships form three themes discussed by the authors; 1) relationships with one's self (for example, personal or spiritual growth as a carer), 2) the care recipient (for example, positive effects stemming from a deepened relationship), and 3) other people (for example, support and recognition from new friends) (Pysklywec et al., 2020). This study provides an essential contribution to this research as it aims to theorise positive effects and emphasises relationality. The authors note that previous studies on positive effects have not entirely accounted for the positive effects of caring within a larger social context, extending beyond the family. They conclude that that positive effects of care can have policy and practice implications; noting that work towards diminishing possible stressors in the carer's life, e.g. financial compensation for family carers, a flexible work environment for employed carers and enshrining the rights of carers into law, may clear the path for the positive effects to germinate by reducing financial or employment-related challenges. The utility of examining well-being in the context of care in later life is highlighted through this understanding of positive effects. As will be turned to in later discussions, recognising the assumed framing of care in later life as negative and burdensome can be examined through the conceptualisation of well-being.

5.3.3 Identity

The literature reviewed refers to the concepts of carer identity, carer values and the concept of self-efficacy. These ideas can be seen to be theoretically rooted in life satisfaction well-being theorisation. However, overall, there is little research on how taking on, living through or exiting care obligations for older family members shape self-concepts, meanings and feelings of mastery or control (Moen & DePasquale, 2017). Where studies do report these concepts, they are examined as an outcome on carers subjective well-being, with studies showing both positive and negative consequences. Davies et al. (2019) carried out twenty semi-structured interviews with carers of people living with dementia. Key themes relating to carer identity are described as 'loss' loss of themselves and their life, present and future and retreating into a world of care leaving previous life and identity behind (Davies et al., 2019).

Using constructivist grounded theory, De la Cuesta Benjamea (2010) studied 22 female primary caregivers of relatives with advanced dementia and their views and usage of respite services. The study found that when female caregivers have legitimate rest, they preserve their identity and make guilt-free decisions. The author examines how these caregivers legitimise taking respite and rest and highlight how the process of taking a break from the heavy demands of caring for a person with dementia has to meet the condition that it is legitimate and is acknowledged by others, and not just by the carer herself, and refers to the moral acceptability of carer rest. The author concludes that taking a rest should not disregard gender norms concerning the responsibility, duty and obligation that women caregivers inherently have. Thus, subjective well-being needs to recognise that carers are subject to norms and obligations that impose a specific type of identity onto the carer. Furthermore, the studies indicate that if carers challenge this identity or do not meet the expectations of this identity, burden and guilt are expressed as a negative consequence (De la Cuesta-Benjumea, 2010).

5.3.4 Self-efficacy Choice and Capacity

The extent to which a person can live the life they want has been shown to influence physical health and overall subjective well-being (Borg, Hallberg, & Blomqvist, 2006). The concepts of choice and freedom to care are examined in several studies using measures such as self-efficacy scales. The consequences of limited choice on carers subjective well-being is reviewed in a study by Ducharme et al., who conducted a quantitative study of 122 caregivers of an elderly relative diagnosed with Alzheimer's disease. The authors used the Revised Scale for Caregiving Self-efficacy, which comprises three subscales for evaluating caregiver capacity to obtain respite from family and friends. The authors note a gendered difference in findings that show that compared with male caregivers, female carers seem to have more problems controlling disturbing thoughts about their new caregiver role and to experience more family conflicts and psychological distress. (Ducharme, Levesque, Lachance, Kergoat, & Coulombe, 2011). These results align with other studies identified (De la Cuesta-Benjumea, 2010) that identify gendered norms that influence the experience of care and outcomes on subjective well-being.

Lim Young (2016) surveyed a sample of 57 female carers in South Korea. Instruments were General Self-Efficacy Scale, Family Scale, and Burden Scale. This study showed that impairments of older adults and caregiver beliefs (strong familism, low self-efficacy) indirectly influenced negative changes in family relationships and social activity restriction through the perceived emotional distress (Lim et al., 2016).

5.3.5 Cultural Values and Beliefs

Cultural values are shown to play an essential role in the consequences on carers subjective well-being and are intimately related to the concept of role identity outlined above. A study by Hasizume (2010) employed a grounded theory analysis of eleven Japanese female working carers to understand the cultural and historical contexts in which female carers experience limited choice in caregiving due to gender and social norms. The concept of "releasing self" was explained as women caregivers adhering to the traditional gender norm of taking sole responsibility for housework, and caregiving was not compatible with the pursuit of their careers and personal life, leaving carers feeling oppressed and not in control. This process of attempting to improve their situation, described as "releasing self," explains how the sociocultural and historical values of family caregiving and gender roles impact the everyday experience of Japanese employed women caregivers (Hashizume, 2010).

Khalaila and Litwin (2011) examined the effects of filial piety on depressive symptoms amongst adult children carers of older parents in Israel. Based on a sample of 265 carers, the authors used filial piety scales and mastery scales to determine the impact that cultural values may have on the mental health of carers. Results show that a sense of mastery mediated the direct effects of education level and gender on depressive symptoms. Filial piety was related to perceived caregiver burden but not to a sense of mastery or depression (Khalaila & Litwin, 2011). Imaiso et al. (2012) provided a further quantitative study of 192 Japanese family carers living in rural and urban regions of Japan. They refer to the concept of *sekentei* or social pressure, and findings based on questionnaire survey results show that *sekentei* was a positive factor associated with care burden (using Zarit burden scale). The authors discuss that in Japan, sekentei or social pressure leads carers to avoid using community resources given the mindset that they must perform the care duties, leading to a higher care burden characterised by depression. The authors continue to explore differences between rural and urban carers use of social support and found that formal home care support was used less in rural communities compared with urban communities. Based on this study, social and cultural pressure to care plays an important role in the carer subjective well-being outcome (Imaiso, Tsukasaki, & Okoshi, 2012).

In a qualitative study by Ali and Bokharey (2015), interpretative phenomenological analysis was used with eight participants of caregivers of people with dementia in Pakistan. Subjective stress was characterised by the following themes: catastrophising, overgeneralising and blaming (Ali & Bokharey, 2015). This study also points to the interaction of subjective well-being with Pakistani cultural values and norms about care. In this way, the study highlights that individual ideas of well-being can be dependent upon and informed by cultural expectations, in this case in Pakistan as the authors point is highly gendered and caring for older people is overwhelmingly expected and carried out by female family members (Ali & Bokharey, 2015).

5.3.6 Caring Context

The significance of the care receiver's condition has been shown in several other studies, with dementia caregivers reporting higher levels of psychological distress and poorer subjective well-being (Schultz et al., 1995; (Pinquart & Sörensen, 2004a). More recent work carried out by Hammond et al. (2014) explored the subjective well-being of carers analysing data from the Personal Well-being Index of 4096 carers living in Australia. Results show a significant interaction between the caring relationship and the type of disability being managed. Those caring for someone with multiple types of disabilities were found to report the lowest level of subjective well-being compared to any other carer group (Hammond et al., 2015). Lavela (2010) carried out a literature review that compared demographically matched married carers with non-caregiving controls. Results showed that adult spousal caregivers experienced more cognitive functioning difficulties, strain, distress, stress, loneliness, depression, anxiety and poorer mental health. Objective measures such as caregivers of spouses with cognitive impairments, mainly wives, were significantly affected by poor psychological health, as were caregivers who were new to the caregiving role and those who rated caregiving as stressful (Lavela & Ather, 2010). Fiona Alpass and colleagues (2013) examined caregiving and health, including mental health, in a large nationally representative sample of older New Zealanders n=2155, which included a large subsample of Māori. They found that level of care operated differentially on mental health status depending on ethnicity and gender. Those providing the highest levels of care (more hours per day more frequently) reported poorer mental health, and the relationship between the level of care and mental health was most substantial for Māori males. (Alpass et al., 2013)

5.4 SUBJECTIVE WELL-BEING SECTION SUMMARY

Based on these findings, care and subjective well-being are mainly viewed from negativity and burden. Furthermore, there is a lack of research studies that attend to carers own beliefs about what constitutes subjective well-being with a predominance of negative well-being, drawing upon the Zarit Burden Inventory and the Pearlin stress models identified in the theoretical literature review Chapter 3.5, as such carer subjective well-being is overwhelmingly defined as the absence of negative feelings or emotions; depression, stress, guilt. Where studies attend to positives, theoretical foundations are fragmented, with most studies emphasising life satisfaction or happiness measures. Furthermore, some indications indicate that praise from others or role fulfilment is vital to positive subjective well-being. There are also aspects relating to feeling valued by others and the important role of cultural expectations in building positive or negative subjective well-being. Gender in this regard is of significance, with female gender expectations providing a backdrop to several studies that aim to make sense of care obligations and subjective well-being. I shall now turn to the second domain of well-being – material and discuss the specific attributes based on the findings of this review relevant to carers material well-being.

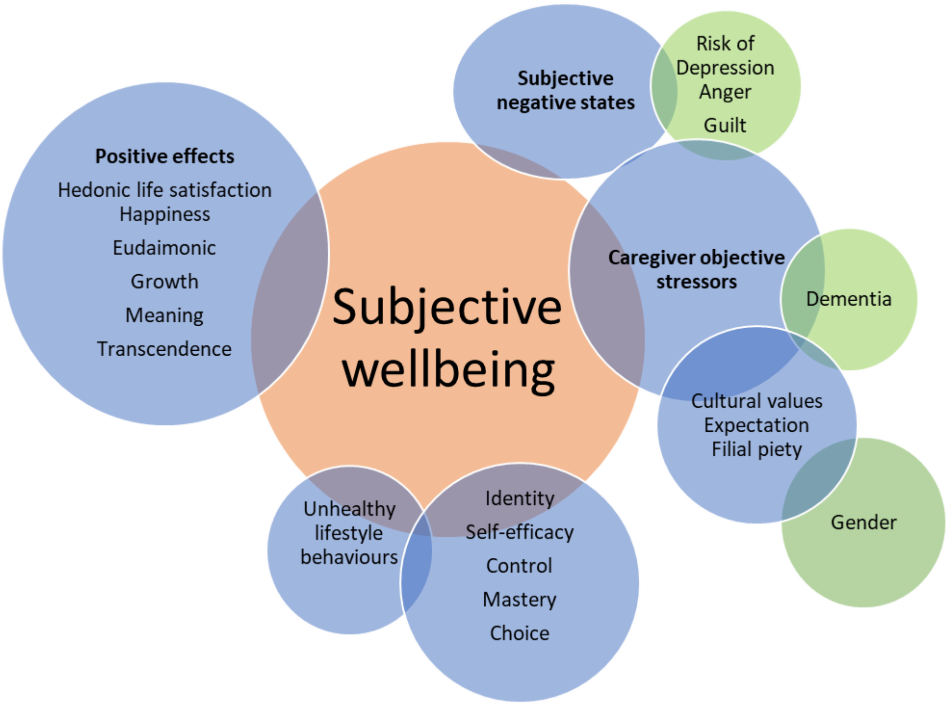


Figure 5 - Empirical Impacts Subjective

5.5 MATERIAL WELL-BEING

The scoping review addresses the knowledge gap identified in the theoretical review in Chapter 2 and 3. Therefore, the review focused on examining articles that explored the interplay between extrinsic aspects of well-being (understood to be embedded in the caregiver's broader socio-political and cultural context) and the subjective domain of well-being. The material and extrinsic aspects of well-being consider factors such as income, wealth, employment and housing and broader social resources and support available to the carer. The findings of the review show that the majority of investigations concerning the material domain of well-being and the consequences of care on material resources demonstrate a negative association between carer burden and lack of specific resources; finances (Keating (Keating et al., 2014), education (Imaiso et al., 2012) and formal support services (Ducharme et al., 2011; Funk, Dansereau, & Novek, 2019; O'Rourke et al., 2021). In their systematic review of 126 studies of the economic costs of family care to adults, Keating et al. (2014) developed three significant categories to define the economic costs; employment, out of pocket and caregiving labour. The authors note that much of the costs of family care lie beyond the formal paid economy and that fifteen per cent of carers reported a high degree of financial hardship. The authors suggest that further research is needed to determine the extent to which carers may be at increased risk of poverty (Keating et al., 2014).

DiGiacomo et al. (2019) examined the financial stress amongst 988 self-identified carers using a cross-sectional sample from the South Australian Health Omnibus Survey (HOS). To determine financial strain, the authors used an instrument that included indicators such as cash flow problems and hardship, e.g. being unable to afford gas, electricity bills and having to seek financial assistance from families and friends. Other indicators are used to show levels of actual deprivation. Results show that out of the 988 carers, 13 per cent reported that they experienced one or more indicators of financial stress. The most commonly reported stress-related indicator was seeking help from community organisations or friends/family, followed by inability to pay bills on time. Furthermore, findings show that carers having financial distress were significantly more likely to provide care for a person with a mental illness and working age carers who spent more time caring each week were more likely to experience financial stress.

5.5.1 Income and Socioeconomic Status

Several studies identified in this review focus on the antecedent factors such as education and socioeconomic status that influence well-being outcomes and belong to the material domain. Brimblecombe and Burchardt (2021) provide a quantitative report and overview focused on inequalities within social care in the UK. They analyse family carer demographics and find that family care responsibilities are not evenly distributed. People living in more deprived local areas are more likely to provide care at a higher intensity than people living in the least deprived areas (Brimblecombe & Burchardt, 2021). Carer educational background was examined in one study by Alrashed (2017). The study aimed to measure the scope of care and enabling arrangements in the lives of 135 caregivers of older people. The results highlighted that healthy life indicators were significantly lower among the no-schooling participants and that older caregivers were associated with weaker enabling variables (Alrashed, 2017). Similarly, in a study of health literacy amongst caregivers of patients with heart failure, Della et al. (2018) found that amongst the 173 caregivers surveyed, caregivers with a low education level showed the lowest health literacy, and this related to the carer health outcomes (Della Pelle, Orsatti, Cipollone, & Cicolini, 2018).

A recent study by Abbing et al. (2021) investigates to what extent educational and income inequalities in the use of formal, informal and privately paid care have changed over time in the Netherlands. The authors report that an increase in inequality was only found in the use of informal care. In contrast, informal care use is stable among lower SES groups; it decreases steeply among higher SES groups. The authors concluded that the findings highlight the importance of education for explaining variation and changes over time in care use (Abbing, Suanet, & van Groenou, 2021).

Further studies identified show that the income and wealth of the carer and the carer's family appear to be of critical significance. For example, in their extensive review, Bauer and Sosa-Poza (2015) found that high family income and strong social support enable families to make choices concerning care and that willingness to care, is to an extent, dependent upon material circumstances (Bauer & Sousa-poza, 2015).

5.5.2 Support to Care

Early work by Cohen (2004) shows how support services can act as a mediating factor helping soften the negative effects of care to family carers (Cohen, 2004). In a country comparison of community care within England, Finland and Australia, Yeandle et al. (2012) and findings report that since the year 2000, carers have gained greater recognition, and new models of carer support have been developed. These systems, the authors note, as 'semi-formalised' support and payments made to family carers are growing. The authors reflect that these developments assist those who prefer to provide unpaid family care but offer limited compensation for carers' financial and other sacrifices (Yeandle et al., 2012). In the UK, carers who do not participate in the paid labour market are entitled to a carer's allowance subject to conditions [8]. It is currently, the lowest universal welfare benefit in the UK at £67.75 per week, this is equivalent to less than £2.00 an hour. Gulland (2021) examining the UK’s welfare systems in relation to unpaid carers suggests they occupy an ambivalent position within social welfare systems and that carers allowance can be understood as little more than an honorarium or a thank you (Gulland, 2020).

A recent study by Liu (2021) used quantitative data of 310 informal caregivers of applicants for social long-term care insurance in Shanghai were interviewed. Univariate and multivariate analyses were conducted to explore the associated factors with the caregivers' life satisfaction. The study found that life satisfaction was consistently associated with monthly income, health status, support and caring hours of the caregivers (Liu, Zhang, Yuan, & Lyu, 2021).

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[8] Conditions include: that the carer spends at least 35 hours a week caring for a disabled person (you don't have to live with them or be related to them), care for someone who receives the higher-rate or middle-rate care component of Disability Living Allowance, either rate of Personal Independence Payment daily living component, or any rate of Attendance Allowance, do not earn more than £132 a week (after deductions), are not in full-time education.

Family carers expressed unmet need concerning information in a study by Rosa et al. (2010) of 112 caregivers of patients affected by moderate to severe dementia. However, the authors found a high incidence of family members who still expressed the need for additional information and support from formal networks about the illness (Rosa et al., 2010). Ducharme et al. (2011) studied the characteristics of the caregiving context during the transition to the caregiver role following diagnostic disclosure of Alzheimer's disease. Data were collected using standardised measures selected following the role transition theoretical framework. The sample recruited comprised 122 caregivers of an older relative diagnosed with Alzheimer's disease. The authors found that most caregivers received little informal support during the role transition to carer, had poor knowledge of available formal services and had difficulty planning ahead for the relative's future care needs. These factors, the authors argue, resulted in experiences of burden and stress for the caregiver. (Ducharme et al., 2011).

Studies identified through the scoping review also point to support services negatively impacting carer well-being. In their study of 122 caregivers of people living with dementia, Funk et al. (2019) provide a qualitative investigation of 32 carers of older adults, the study examines how family carers navigate formal support services, and the authors apply the analytical concept of 'structural burden' to identify the process of accessing and receiving resources. They found that family carers can experience the process of service navigation as an additional form of burden that is structural in origin (Funk et al., 2019). Further studies identified in this review concerning structural burden are provided by Cohen et al. (2016), who highlighted caregiving burden stemming from negotiating Medicare and Medicaid (Cohen, Colby, Wailoo, & Zelizer, 2016). Similar findings were reported in the UK by Laparidou et al. (2018). Using focus groups and face-to-face interviews (n=18) with caregivers, the authors found that several factors, including fragmentation of services, results in support services only partially fulfilling their role of support for the family carer of a person with dementia leaving significant unmet need. The study also points to the need to pay for support services such as respite care, help around the house and use of wheelchairs for the care receiver. They conclude that lack of support may intensify caregiver stress and worsen health and well-being outcomes. (Laparidou, Middlemass, Karran, & Siriwardena, 2018).

A recent study by Midtbust et al. (2021) carried out a qualitative analysis based upon in-depth interviews with ten family caregivers of residents in three Norwegian long-term care facilities. The authors found admission to a long-term care facility became a painful relief for the family caregivers due to their experiences with the poor quality of palliative care provided. The lack of meaningful activities and unsatisfactory pain relief enhanced the family caregivers' feelings of responsibility and guilt. Despite the insecurity regarding the treatment and care given during the early phase of the stay, the family caregivers observed that their close family members received high-quality palliative care during the terminal phase. The family caregivers wanted to be involved in the care and treatment, but some felt it became a heavy responsibility to participate in ethical decision-making concerning life-prolonging treatment. (Midtbust, Alnes, Gjengedal, & Lykkeslet, 2021) .

Finally, O'Rourke et al. (2021) report on qualitative research that aimed to examine the impact of the Care Act 2014 on carers in four English local authorities. Based on case study analysis, findings show that caring is regarded as an activity that crosses a perceived moral boundary between public and private domains and calls for appropriate policy responses. The authors conclude that caring is recognised in the English welfare system as a social risk. However, it is not always treated as one in translating policy into practice. This is seen in how the aims of carer support were defined and understood at a local level, with a primary emphasis on the goal of maintaining carers in their caring role through supporting resilience and promoting self-help (O’Rourke et al., 2021).

Based on the identified studies, the evidence suggests that a lack of resources coupled with complex, fragmented systems cause and exacerbate carer burden and stress, negatively impacting their well-being. The empirical work provided in these studies offers essential foundations for assessing the outcome of service support on family carers and points to the need to understand that support policies and services can have unintended consequences (Oliver et al., 2019).

5.5.3 Employment

Employment consequences have been studied extensively amongst the studies identified (Yeandle et al., 2017). Evidence suggests that consequences of family care on carer employment include factors such as; withdrawal from the labour market, restricted working hours, decreased productivity and limited career prospects (Keating et al., 2014). Bauer and Sousa Poza (2015), in their review of the empirical literature on caregiver Employment, Health, and Family, identified longitudinal data that can determine causal links between paid work and negative associations on the carer through a reduction in hours or exit from the labour market. However, the authors reflect on overall findings and caution that the evidence relating to outcomes on employment is mixed with some reviews finding effects of caring to be overestimated. Furthermore, the authors found evidence to demonstrate that carers generally have lower employment levels than non-carers which implies that they would be unable to increase their participation in paid work even without caregiving (Bauer & Sousa-poza, 2015).

In the UK, there is an increasing policy emphasis to deliver support packages to carers that enable them to participate in the labour market in the form of 'replacement care'. Pickard et al. (2018) find in their mixed-methods study of carers and employment in the UK that where replacement care was not provided to the cared for, the carer was subsequently more likely to leave employment because of caring, suggesting that the absence of services contributed to the carer leaving work. The authors conclude that if a policy objective is to reduce the number of carers leaving employment because of caring, there needs to be greater access to publicly-funded services for disabled and older people who are looked after by unpaid carers (Pickard, Brimblecombe, King, & Knapp, 2018). Studies identified also show that the effect of caregiving on employment time and wages often differ between men and women, with women more likely to reduce their labour market participation after becoming carers. In one study, both male and female carers received 6 per cent less through estimating the opportunity costs of caregiving through wage reduction (Heitmueller & Inglis, 2007).

Similar results were found in a study by Schneider et al. (2013). They showed that carers consequences on employment prospects are highly gendered, with male and female employees experiencing conflict between work and care differently. Using data from a sample of 471 caring and 431 noncaring employees in Austria, the authors found different aspects of informal caregiving associated with job changes and the anticipated labour market withdrawal of male and female workers. Intentions to exit the labour market of male workers appeared to be triggered by a physical care burden rather than time demands. A time-based conflict between care and paid work was significantly and positively related to the intended job change of female workers but not of their male counterparts. Flexible work arrangements were found to facilitate the attachment of female workers to their jobs and the labour market (Schneider, Trukeschitz, MÃ¼hlmann, & Ponocny, 2013)

5.5.4 Health

In the conceptualisation of well-being, health is included as a material resource. Overall, the evidence surveyed points to a paucity of studies relating to physical health outcomes of family carers, and this aspect of caring has received less attention than studies on psychological health (Bauer & Sousa-poza, 2015; Caceres et al., 2016). Studies generally focus on the interaction between physical health and mental health, aiming to establish causal relationships. Research generally shows a correlation between time spent on caring with negative consequences on physical health. Vlachantoni et al. (2016) investigate the association between past and present family care provision and poor health, and the study reports on carers self-reported health at two-time points (2001 and 2011). The key findings show that heavy carers (more than 20 hours per week) in 2001 who were not caring in 2011 exhibited 22% higher odds of reporting poor health in 2011 than non-carers -carers with modest differences between men and women. The study highlights the important role of the intensity of care provision when considering the health outcomes associated with a particular caring role (Vlachantoni, Robards, Falkingham, & Evandrou, 2016).

Risk of frailty and caregiving has been examined in a recent study by Barbosa et al. (2020). Using sample data (*N* = 52,073) from 17 European countries that participated in wave 6 of the Survey of Health, Ageing and Retirement in Europe (SHARE), the authors applied a multinomial logistic regression to estimate caregivers' chances of frailty. The results show that the prevalence of pre-frailty and frailty differs according to the caregiver's status, gender and the European region. The highest majority of pre-frailty was found in female caregivers from Northern countries (57.3%). The highest prevalence of frailty was found in female caregivers from Southern countries (29.3%). Providing co-residential care is positively associated with the risk of being pre-frail in women in all European regions. The results of this study suggest that female co-residential caregivers are at a greater risk of being pre-frail in all European areas except Southern Europe, where male and female co-residential caregivers are at a greater risk of being frail compared with non-caregivers. European policymakers should create political measures to prevent and reverse frailty among European co-residential caregivers (Barbosa, Voss, & Delerue Matos, 2020).

The interaction between physical and mental health has been the focus of a large body of literature concerning health and has been analysed in several meta-reviews; Pinquart and Sorenson (2003) conducted a meta-review of the literature relating to family caregiving and its impact on health and concluded that negative physical health consequences are due to mental health status than to overload or physical strain (Pinquart & Sorensen, 2003). The complex connections between physical and mental health are elaborated upon further in several studies that look at the physical outcomes of mental distress. Vitaliano, Zhang and Scanlan (2003) carried out a meta-analysis of 23 caregiver studies on caregiver health. The authors compared 1,594 caregivers of persons with dementia with 1,478 demographically similar non- caregivers. Across eleven health categories, caregivers exhibited a slightly greater risk for health problems than non-caregivers. Overall, caregivers reported more health problems than non-caregivers, with caregivers showing a greater potential illness risk than non-caregivers. (Vitaliano et al., 2003).

Furthermore, they analysed demographic variables as moderators of caregiving relationships with health indicators and found female caregivers (n = 500) reported poorer global health than male caregivers (n = 262). The authors formulate a theoretical model that relates caregiver stressors to illness and identifies moderating roles for vulnerabilities and resources and mediating roles for psychosocial distress and health behaviours. This is important because the study points to the interconnectedness of the caregiver material resources to their self-reported physiological health measures. A further study demonstrating the interaction between physical and mental health is offered by Erlingsson et al. (2012), who report on findings of a literature synthesis on the health of Swedish family caregivers. The results of the 31 articles reviewed show that caregivers beliefs about reciprocity feelings of responsibility and guilt have a profound impact on physical health (Erlingsson, Magnusson, & Hanson, 2012).

A study by Ali and Bokharey (2015) using interpretative phenomenological analysis showed that subjective stress, characterised as; catastrophising, overgeneralising and blaming, led to participants describing chronic fatigue and sleep disturbance which was found to be significant to physical health (Ali & Bokharey, 2015). A differential effect of gender was found by Juratovac et al. (2015), who studied 46 full-time employed female carers. The results found that the most common conditions for the 28 females who described their health were back pain and arthritis, followed by fatigue and tiredness (Juratovac & Zauszniewski, 2014). Similar results were found by Caceres et al. (2016), who carried out an integrative review of 11 articles of family caregivers of frontotemporal dementia and found that female caregivers were most likely to experience decreased sleep as a result of the behaviour of the care receiver (Caceres et al., 2016). Overall, the findings relating to health outcomes of care point to a complex interplay between material resources and subjective well-being measures. Gender-based analysis shows differences in the extent and severity of these outcomes.

5.6 MATERIAL WELL-BEING SECTION SUMMARY

The literature on the consequences of carer well-being within the material or objective domain points to negative impacts concerning income, employment and health. Particular features of well-being in older people relate to the condition of the cared for, and the literature evidences challenges and risks to adverse outcomes. Accessing and experiences of support services designed to alleviate or mitigate risk have been shown to present additional barriers and result in experiences of stress and adverse subjective well-being outcomes. The literature has not fully theorised or attended to the relationship between these extrinsic aspects of carer well-being and subjective well-being.

Figure 6 - Empirical Impacts Material

5.7 RELATIONAL WELL-BEING

Relational well-being accounts for social relationships and interactions and enables individuals to translate material things into valued outcomes or functionings. As outlined in theoretical discussions in Chapter 3.6, adopting a relational element to accounts of well-being begins from the assumption that to be well, we need supportive connections with others (Keating et al., 2021). The literature focuses upon three critical aspects of relational well-being; 1) the condition of the care receiver, 2) the carer's relationship to the cared for, and 3) if the carer and cared for live in a shared household. Early work provided by Hirst (2005) found that care provided to someone inside the household is the most intensive type. Spousal caregivers are particularly at risk of negative outcomes compared to non-resident carers (Hirst, 2005). A later review study by Anker and Hansen (2016), based upon 16 studies on carers relationships, found that carers who were not cohabiting with the person they care for can become socially isolated (Anker-Hansen, Skovdahl, McCormack, & Tønnessen, 2018). A further recent review by Keating and Eales (2017) based upon synthesising 66 articles on social relationships and carers and highlighting key themes from the literature; changes in relationships with family members, changes in marital relationship with the spouse care receiver, and changes in social networks connections. (Keating & Eales, 2017b). Abad-Corpa et al. (2012) reviewed 20 qualitative studies to understand the process of adaptation to dependency in older adults and their families. The authors identified the central theme based on the analysis as 'caring to achieve the maximum independence possible'. The findings show an interconnected picture of physical, material, social and emotional aspects of care; and the profound social and relational impact of providing and receiving care. (Abad-Corpa et al., 2012).

5.7.1 Condition of the care receiver

The studies suggest that the cared-for condition plays a particular impact on their relational aspects of carer well-being. Lim et al. (2016) studied 157 female caregivers of older adults in Korea. They found that carers of older adults with high impairments in ADL showed perceived embarrassment related to the poor social functioning of older adults, resulting in social activity restriction. The results also indicate that family caregivers caring for older adults with high cognitive impairment perceived stress due to the disruptive behaviours of older adults, ultimately leading to negative changes in family relationships (Lim et al., 2016). A recent study by Zwar et al. (2021) examined the public stigma of carers providing care to those aged 65 and over in Germany. Drawing from a participant sample of 1038 participants, the authors assessed public stigma towards informal caregiving for individuals aged 65 years and older using three scales. This study elucidates specific factors concerning caring for an older person. The results show that there is stigma towards informal caregiving for older individuals (65 years and older) in terms of emotional reactions, cognitions and social distance. The implication of stigma towards carers of older people is understood as vulnerability to social isolation. (Zwar et al., 2021).

Davies et al. (2019) refer to previous literature that shows that dementia caregivers are at particular risk of disruption of social networks and resultant isolation and loneliness (Davies et al., 2019). They explore temporal aspects of carers' relational well-being in a qualitative study of 20 family carers of people living with dementia in England. The overarching theme of 'separating worlds' is identified, referring to the internal caring world and the outside world of society. Extracted from the data are four further sub-themes; the support role of relationships and social networks, loss as a consequence of caring, reconstruction of life as a carer and life within and beyond the computer screen. Furthermore, the authors argue that the internet could be a viable option to help carers maintain existing networks. Finally, as the care recipient condition worsens, particularly concerning dementia, the lack of social networks can be heightened towards the end of life. (Davies et al., 2019).

5.7.2. Loss, Isolation and Loneliness

A consequence on carer relational well-being was consistently analysed through the concepts of loneliness, isolation and exclusion and the impact of the loss of social relationships. In a recent study looking at resilience, Joling et al. (2017) found a positive relationship between perceived loss of social relationships and feeling isolated amongst 1,048 caregivers from a harmonised data set from the UK and The Netherlands (Joling et al., 2017). In their systematic review, Lavela and Ather (2010) identified studies that demonstrated a dynamic relationship between caregivers experience of loneliness as a predictor of depression and poor psychological health. Furthermore, they found differential effects based on gender, with caregiving wives indicated having a more significant loss of self and more loneliness and depression than caregiving husbands, and loneliness was the only predictive variable for Alzheimer's Disease caregiver depression (over and above being wife caregiver (Lavela & Ather, 2010).

Bauer and Sousa-poza (2015) argue that the effects of caregiving must incorporate caregivers' families and formally supported alternatives (Bauer & Sousa-poza, 2015) and the need to feel supported by close family (spousal or non-spousal) is a recurrent theme in the literature reviewed. Anker-Hansen et al. (2017) synthesised literature relating to the needs of care partners of older people living at home with assistance from home care services. The systematic review of qualitative and quantitative studies revealed three main categories; the need for quality interaction, the need for a shared approach to care and the need to feel empowered. The authors conclude that concerning these categories that the carer has severe unmet needs (Anker-Hansen et al., 2018).

Marriage has been shown repeatedly in the literature to play a mediating effect on the negative consequences of care. For example, Anderson et al. (2017) explored the impact of stroke on the married relationship and, based on constructivist grounded theory analysis of interview transcript's with 18 couples of long term marriage, concluded that marriage relationships are fundamental to the management of impairments and the well-being of the couple (Anderson et al., 2017). In the US, nearly one-quarter of caregivers aged 65 years and older provide care for their spouse (Lavela & Ather, 2010) and the type of family relationship that has been most consistently reviewed in terms of its effect on caregivers the health and well-being of the caregiver is the spousal married relationship (Bauer & Sousa-poza, 2015).

Despite findings that show the protective nature of marriage, some reviews found damaging effects on relational well-being. For example, Keating and Eales (2017) study showed evidence of risk of marriage breakdown as a consequence of the caring role referring to lack of emotional support, loss of affection and intimacy and a reduced sense of reciprocity as some of the critical elements affecting the marriage relationship of spouse carers (Keating & Eales, 2017b).

5.7.3 Social Relationships and Networks

The literature highlights social relations and networks as key to mitigating the risk of burden and isolation. However, a simple divide in the literature can be drawn between the social networks that refer to close friends and family and relationships with networks that are more expedient in nature, for example, health and social care professionals. As previously outlined, expedient networks provided by professionals has been examined, and evidence shows that carers can experience 'structural burden' (Funk et al., 2019) when accessing support services, and evidence suggests that connections to formal support networks can fail to meet need causing mental distress.

5.7.4 Time and Respite

The time spent on caregiving and the restrictions on the caregivers' personal time were the main variables related to carer burden under relational well-being. The notion of limitations on the caregivers time is a common theme within the literature. It is referred to as a critical determinant of burden and stress. (Bartolo et al., 2010). Respite is a crucial intervention that can support carers regain balance and pursue socialising and interests beyond their caring responsibilities. As such, it is a component of relational well-being. It also relates to domains of subjective well-being - time away from caring can maintain a sense of self-identity and self-efficacy and is further elaborated on within the following section. De la Cuesta Benjamea, (2010) found burden and guilt associated with respite in their study of twenty-two female primary caregivers of relatives with advanced dementia who participated in semi-structured interviews in Spain. The authors conclude that when female carers have legitimate rest, they preserve their identity and make guilt-free decisions. The authors note that what gives rest to caregivers and this occurs is not fully known. (De la Cuesta-Benjumea, 2010).

In recent years, care theory has advanced the understanding of care as a non-linear, non-static and malleable experience (Bowes, Dawson, Ashworth, 2019). This is important because changes in the relational aspects of a carers well-being vary in part because of temporal changes. For example, Crawford et al. (2015) interviewed twenty caregivers of people with dementia who had recently been admitted to a long term care facility in Victoria, Australia. Results suggest that at the transition to their new role of visitor, caregivers can experience loneliness – after the care receiver goes into the home. (Crawford, Digby, Bloomer, Tan, &

Williams, 2015). Similar results are found in a study by De Rooij et al. (2012), who found that the caregiving role of family members is not relinquished when their partner or parent with dementia enters the residential facility, building partnerships between residents, families and staff. This study focused on family caregivers related to these residents (n = 64), with the majority of the participants expressing loneliness and a sense of loss when the care receiver enters a care home (De Rooij et al., 2012). These findings suggest that it takes time for the impacts of caregiving to manifest in any measurable magnitude the care experience is malleable and changing according to different caring contexts.

5.7.5 Cultural Beliefs

The role of cultural beliefs and values emerged as a finding within the literature analysed, and carers subjective beliefs regarding coping and burdening family and friends were identified as impacting relational well-being. Erlingsson et al. (2012) show how the ability to maintain social networks changes and diminishes over time and is compounded by the caregiver's beliefs that they should not burden children, friends, and neighbours. Results indicated that carers beliefs, together with the quality of relationships and feelings of responsibility and guilt, have a profound impact on their health (Erlingsson et al., 2012). Ducharme et al. (2011) found that a significant number of carers interviewed said they avoid asking their family for help for fear that it would breed conflicts. This study also showed that female caregivers reported significantly more family conflicts than male caregivers (Ducharme et al., 2011).

5.8 RELATIONAL WELL-BEING SECTION SUMMARY

To summarise, in the relational domain, the care receiver's condition requires focused attention, particularly for carers of people with dementia, where evidence shows carers withdrawing from social networks due to embarrassment or stigma surrounding the disease. Issues relating to the complex interaction between the influence of cultural beliefs on the ability and willingness to access and gain support and respite from caring are explored. Carers sense of self-identity beyond 'care' are found to be important in pointing to a broader context on which to understand carer well-being. Finally, recent literature discusses care-related issues as a non-linear experience where relationships change and are curtailed and influenced by the variations in the caring context.

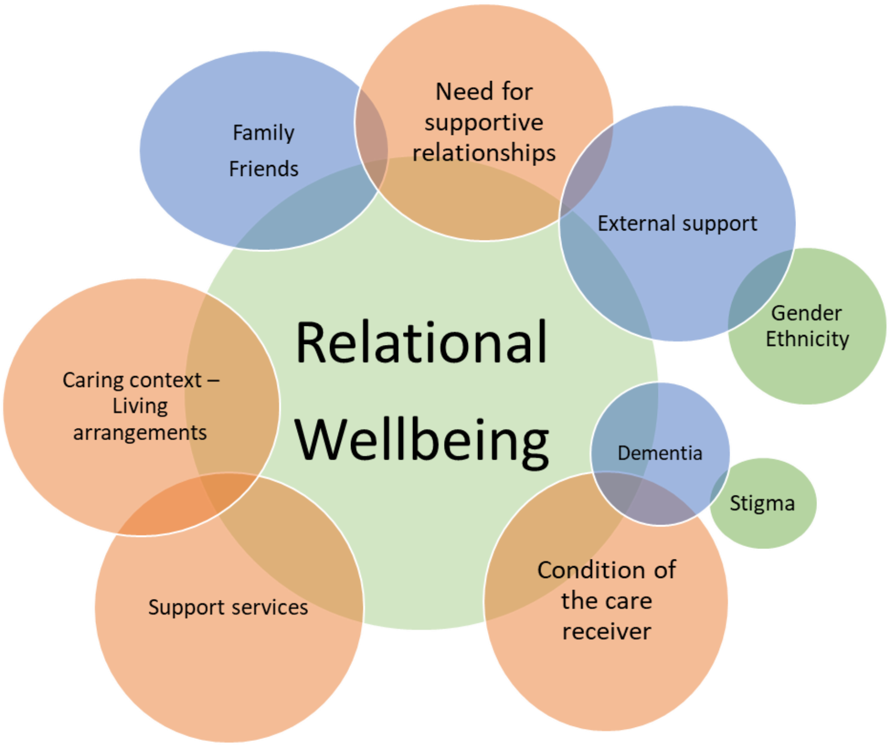

Figure 7 - Empirical Impacts Findings Relational

5.9 CONCLUSION TO CHAPTER FIVE – EMPIRICAL IMPACTS ON CARER WELL-BEING

I began this chapter by outlining a framework of analysis for developing well-being domains for family carers. This analysis has been applied throughout the scoping review to identify how the empirical literature on the consequences of family care informs understanding of well-being. I organised the review around the major domains of well-being, subjective, material and relational. The three domains were used to organise and 'hold the data'. It is acknowledged that there are several levels of interconnectivity between the properties of well-being identified and domains.

The well-being empirical analysis findings are summarised below:

Subjective well-being

- Both positive and negative aspects characterise subjective well-being
- Subjective well-being is a particularly complex domain of well-being, and to date, the literature on carers remains entrenched within the burden discourse.
- Broadly, outcomes relating to subjective well-being are characterised by depression, anxiety, stress, sleep disturbance, guilt and anger.
- Although there is evidence of the value and benefits that care can bring to subjective well-being, a lack of theoretical foundation or universal agreement on what constitutes positive attributes of subjective well-being make it challenging to move beyond qualitative descriptive studies.
- Positives are identified within both eudaimonic and hedonic well-being traditions.

Material well-being

- Material well-being literature is dominated by resources carers have, and evidence shows carers experience negative effects from care.
- Support services play a significant role in material well-being, and this review has found that in many ways, support services compound burden of caregiving.

- The evidence suggests that a lack of resources coupled with complex, fragmented systems cause and exacerbate carer burden and stress, negatively impacting their well-being.
- The work of Funk et al. (2019) provides an essential theoretical foundation on which to assess the outcome of service support on family carers and points to the need to understand that support policy and services can have unintended consequences (Oliver et al., 2019) that impact particular for carers on their finances (through out of pocket expenses for services) and mental well-being (characterised as stress and burden).
- A connection can be made to material well-being accounts and culture's role in accessing support services. For example, evidence suggested that it was culturally inappropriate to ask for help (filial piety, the idea of duty, etc.).

Relational well-being

- There is a paucity of evidence relating to this domain of well-being.
- The majority of studies focus on the carer experiencing loss of social networks.
- There is evidence demonstrating strain and negative effects on close family relatives. Furthermore, evidence shows that the caring context was particularly significant, with carers who share the same household as the cared for, vulnerable to negative effects.

In considering the theoretical implications of this review, the limits of theorising well-being in the context of older age based upon a burden frame have been outlined and are founded upon two central problems; 1) burden results in overwhelmingly negative accounts of care so unable to identify the positive value of care in older age and 2) individualises the negative consequences of care thereby limiting understanding of carer inequality.

Based on the findings of this review, I suggest that the negative outcomes of care can be understood as a result of increased risk to a particular set of *vulnerabilities* to harm rather than burden. Drawing upon vulnerability theory developed by care ethicists and capabilities theorists (Engster, 2019; Fineman, 2010; Mackenzie et al., 2014), this notion of vulnerability does not deny the universal experience of vulnerability that care ethicists theorise instead expands the analytical framework and supports acknowledgement and understanding of how carers experience adverse outcomes.

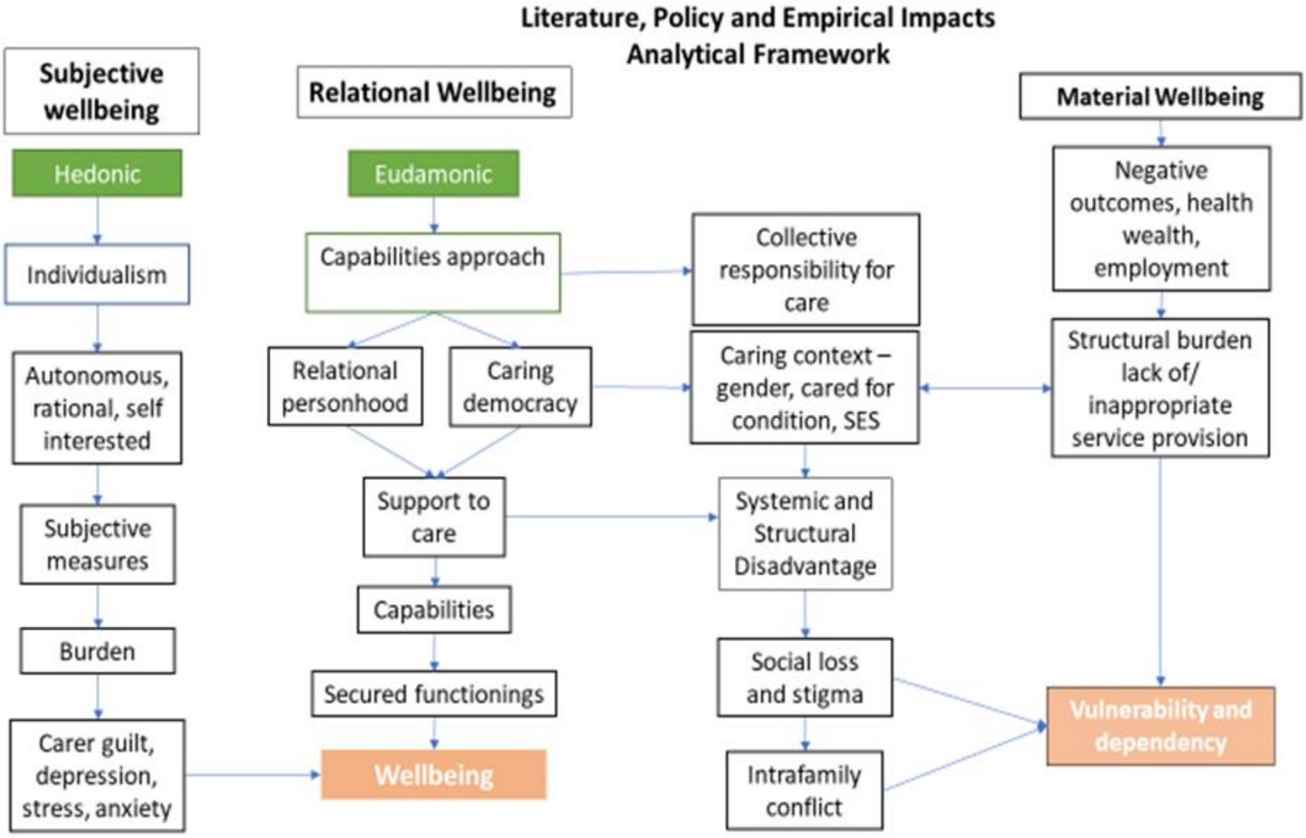

Figure 8 - Analytical Framework

CHAPTER SIX - METHOD

6.1 INTRODUCTION TO CHAPTER SIX

This chapter outlines the study's core methodological position and the methods selected. First, I reiterate the study aims and objective to demonstrate the rationale for selecting the chosen methods. Next, I reflect upon and discuss my personal and professional experiences of care and my current role as a volunteer for a local carers charity. I finish this section by identifying the study's key ethical issues and implications, and a detailed account of the process of data analysis is presented. Finally, this chapter concludes by presenting data validity and reliability.

6.2 ONTOLOGICAL APPROACH –CRITICAL REALISM

Ontology is the nature of being and representation of reality; epistemology is the relationship between reality and the researcher and the best ways to discover valid knowledge about the world; "Is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate." (Carson, Gilmore, Perry, & Gronhaug, 2001). The study's ontological position is critical realism. Sitting alongside ontology is epistemology; this helps inform the theoretical perspective taken and guide the overall research design. Positivism and interpretivism are two common approaches to epistemology (Carson et al., 2001; Wheeldon & Ahlberg, 2012).

This study begins from a critical realist (CR) position, that is, in broad terms, a philosophy and social theory founded upon the fundamental precept that reality exists independently of social processes, actors, or environments (Archer, Bhaskar, Collier, Lawson, & Norrie, 2013; Bhaskar, 2010, 2013; Danermark, Ekström, & Karlsson, 2019; Ryan, 2019; Sayer, 1997). This is in direct contrast to 1) constructivism - that all meaning and reality is socially constructed and 2) positivism – that the social world can be observed through our empirical sense experience of it. British rationalist philosopher David Hume (1711-1796) is understood to have developed the empirical model that positivism is rooted within. This model understands that reality can be known through our sense (empirical) experience. It rejects the application of theory (except hypothesis) to the observed objects of the world (Alderson, 2021).

This study adopted the CR perspective because of its focus on exploring the socio-political and cultural influences that affect the meaning. These are not necessarily verifiable through empirical measurement. In this way, a positivist approach would be unsuitable for this study. As Margaret Archer explains, "Many of the determinate and important features of the world are not empirically verifiable or quantifiable, and may, in fact, resist articulation into theory, language, participants, models, or empirical scrutiny (Archer et al., 2013). An alternative approach is constructivism that asserts that all meaning, and reality are socially constructed, and there is no separate reality that can be observed.

Furthermore, how we see the world directly affects the way in which the world is (Elder-Vass, 2012). In this way, human agents are not separate from social structures. Constructivism does not account for the causal powers that structures have, they uncover the effect, but there is no room for human agency and can be understood to render individuals helpless or pre-determined in that individuals cannot challenge the oppressive features identified. This study is focused on care and ethical and justice-related aspects of care. A constructivist account of reality capture only a small part of a more profound and vaster reality (Fletcher, 2017). And finally, as Alderson notes, constructivists can be understood to overlook how social and economic structures exist in and through the activity of human agents; governments depend upon their voters, and companies rely upon their workers and consumers (Alderson, 2021).

Roy Bhaskar (1975), a leading contemporary founder of CR, challenged positivism for its' 'epistemic fallacy' (Bhaskar, 2013), that is that it assumes that our understanding of the world emerges from our thinking or thoughts about the world, thereby collapsing our ontology into our epistemology. Fletcher further explains this critical point that demarcates constructivism and positivism from CR; "Despite the seeming opposition between the constructivist and positivist perspectives, each reduces reality to human knowledge, whether that knowledge acts as lens or container for reality." (Fletcher, 2017, p. 4). On the other hand, CR separates our thinking or epistemology from the independent world of being and doing or our ontology. This, Alderson notes, we can discover but not invent (Alderson, 2021). Bhaskar and CR tradition believe that it is misleading to even think of the 'empirical world'. Accordingly, the world can be known, understood and challenged independently and without our empirical (sense-based experience) of it. In this way, the reality remains 'mind independent' (Sturgiss & Clark, 2020). However, our understanding of and description of that reality is mediated through social processes and layers of interpretation (Oliver, 2012). The central tenet of CR is that ontology (truth and reality) is not reducible to epistemology (our knowledge of that reality); reality exists independently of our knowledge, awareness or ability to survey or appreciate it.

A final point to highlight made by Andrew Sayer (1999), a contemporary CR theorist and responding to the often-misunderstood aspect of critical realism – that is that there is a knowable infallible truth. Sayer points to the very fact that the knowledge we have is fallible that demonstrates that there is a reality that does exist regardless of what we think about it, thus from a CR perspective, all knowledge is shifting and fallible (Sayer, 1997).

CR can be understood as marrying the two positivist and constructivist accounts together and adding a third level of unseen causal influences or mechanisms (Alderson, 2021). Bhaskar's CR understands the world as the complexity of multiple layers of intersecting forces. It begins from the complex and progresses to more fundamental levels of understanding. Structures can be broken down into stratified layers, the first a 'which operates at a higher ontological level, and all phenomena can be referred back to this generative mechanism. An empirical domain occurs whether or not they are experienced and an underlying real domain of structures generating these events (Carolyn, 2012, p. 375).

Furthermore, CR can be seen to respond to the 'problem of agency' – that is, individuals and individual acts can act independently of structure. Garret (2016) argues through a critique of the discourse of 'resilience' and applied to social welfare policies in the UK that there is a tendency in social work practice in contemporary British society to cast social problems as matters of individual behaviour and focus on the individual. I understand this similarly concerning the study's focus on the 'crisis of care' or problem of care in older age. This, I suggest, can also be too readily understood as a 'problem of the old' resulting in the individualism of care. 'Active citizenship' like resilience can be understood as the discursive grounds of individualism in care. A CR perspective can support examining the unacknowledged or assumed value-laden discourse of individualism (in this case, 'active citizenship') and identify and acknowledge structural and material mechanisms that result in inequalities and injustice.

Although not attached to any method or tool through its foundation of understanding the world as working independently of our knowledge, empirical and quantitative methods are generally not subscribed (Fletcher, 2017). CR is, however, understood to support three primary methods: 1) Induction – observation of the world and phenomena, 2) Deduction – a hypothesis of the phenomena and 3) Retroduction. This latter method involves looking for evidence of the unseen cause, working out an explanation and imagining new possibilities. Retroduction encourages a line of enquiry that runs alongside positivist and interpretivist tradition. It looks to answer the question of the phenomena; "What must the world be like for this to occur?" (Alderson, 2021, p. 55). This retroduction step leads to the unseen causal mechanism referred to by Anderson as political economy effects. These political economy effects are often referred to as 'upstream causes'. These include decisions about tax, state supports and services and how these are distributed between classes and regions. (Op cite, 57). CR position supports the study's focus on the upstream causes referred to here by Anderson and responds to the problem of agency that I briefly outline below.

6.3 RATIONALE FOR CRITICAL REALISM

There are three principal reasons why CR critical realism is particularly suitable methodological position to base this study upon. Firstly, the CR emphasises understanding reality and causal analysis focused on empirical description and engages critically with explanations that make it a particularly suitable approach and fit for the subject of this inquiry. As described in the policy analysis, family carer well-being can be understood as a political valence issue (Chaney, 2017). There is little disagreement on the need to promote and safeguard family carer well-being. However, the ideologies and values that underpin these approaches are value laden. This study aims to critically engage with the unseen, socio-political and cultural processes and mechanisms to explain.

Secondly, CR has an emancipatory element to it. The process of retroduction involves a concern with challenge and transformative social action. Caroline Oliver (2012), a contemporary CR theorist, argues that this moves the researcher beyond 'detailed description.' It aims to understand existing social structures by providing a framework wherein surface appearances may be challenged by examining the structures that generate them (Oliver, 2012). Finally, the idea contained within CR of retroduction entails a 'process of democratisation' as Anderson claims: "The process of retroduction involves expert and lay people working out together what the world must be like if we are to promote general well-being. it advances the minority view that radical change is urgently needed to promote equality and justice." (Anderson, 2021, p, 63).

CR is an appropriate methodological approach for this study. Firstly, a constructivist and interpretivism approach lacks the necessary purchase or any emancipatory element to it since all knowledge is contextually and socially constructed, there can be no claim to truth or reality, thereby divorcing the social scientist from explicitly addressing the very problems that their social research addresses (Bloor, cited in Silverman, 2016). Secondly, my professional background and personal convictions have engendered a commitment to responding to social injustice. In this way, critical realism offered me a philosophical orientation that supported challenges to the reality of injustice that carers experienced and that I identified through the study. Finally, this research study is exploratory and seeking to understand meaning, assumptions and values relating to care and well-being in the context of older age. These questions inevitably lead to a qualitative research design.

6.4 CHANGES TO THE ONTOLOGICAL POSITION

I began the study with a social constructivist standpoint and subsequently devised a research strategy that incorporated a grounded theory approach. I carried out a grounded theory approach to understand the empirical outcomes of care on carer well-being (Chapter 5). However, an immersion within the care ethics literature led me to specific theoretical hypotheses that I could not divorce from my interpretation of the scoping review results and findings. This runs counter to the essential data-driven approach to theoretical insights typified by the constructivist and grounded theory methods. Although contemporary grounded theory approaches confirm the use of theory to 'sensitive the data' (Charmaz, 2006), I understood the role of theory in this study as more central than an orientation of the data. CR begins with actively engaging with explanatory theory. I reflected upon my ontological position and acknowledged the major role of theory (feminist ethics of care and social justice informed capabilities approach to well-being) within this study. This led me to consider the ontological position offered through a CR approach. I identified it as an approach that could reconcile my theoretical insights (based on understandings and interaction in the field of enquiry, see research reflexivity section below).

This study has thus emerged as more aligned with the theory centric CR position, rather than avoidance of theory-driven grounded theory approach. Finally, an essential aspect of CR that corresponded to this study lies in CR emancipatory element. This is its' challenge to injustice that offers opportunities as researchers to describe and provide tools for positive change. Together these reasons led me to choose a CR position over the social constructivist and grounded theory methodological approach.

6.5 CRITICAL REALISM - CRITICISMS

Fletcher notes that few authors have demonstrated how CR ontology and epistemology informed their data collection and data analysis, e.g. coding (Fletcher, 2017), and thus challenges to CR have focused on a lack of connection to a specific method, and it has been suggested that it is; "A philosophy in search of a method" and this can be thus understood to limit its application (Carolyn, 2012). In recent years, however, there has been a growing scholarship that evidences applying a CR philosophical position to a wide variety of methods, including grounded theory and various disciplines such as social work practice (Lawson, 1999). For example, Amber Fletcher (2017) applies CR to a qualitative study of Canadian farm women's experiences with agricultural policy. Fletcher notes the lack of detailed reflection and application of CR within research and aims to distinguish a specific set of methods that advance the CR approach within social science. This approach is typified by what Fletcher refers to as; "A type flexible deductive process of coding and data analysis." (Fletcher, 2017, p. 3) consistent with CR ontology and epistemology. And Fletcher argues, the methodology provides a concrete example of applied qualitative research using CR as a philosophical and methodological framework (Fletcher, 2017). This study offered beneficial insights to data analysis of interview transcripts, and I adopted some of the methods outlined.

6.6 RESEARCH REFLEXIVITY

Researcher reflexivity is understood within health and social science as the process of attending to the researchers' influences during the research project (Finlay & Gough, 2008). It recognises and emphasises ongoing questioning of one's place as a researcher and power relations within the research process. The idea of reflexivity and the extent to which it is judged as good for the research or as clouding and negatively impacting the course of inquiry depends upon the researcher's ontological position. Max Weber asserted that as social scientists, we should strive to rid ourselves of values when undertaking research. Doing so would make our research good (Allen, 2004). Opposing this view is grounded theory accounts or constructionists that understand the researcher as meaning-making, involved in the research process.

As set out above, I assume a position of critical realism for this study: there is a reality that can be known but cannot necessarily be understood through empirical judgment or interpretation alone. Based on this ontological position, the question of reflexivity then becomes a question of which parts of my value judgements and experience of the research phenomena were a problem or threat to the validity of the research analysis and subsequent findings. Reflection is essential to understand the researcher's role and the potential imposition of values and ideas in the production of meaning-making (Corbin and Strauss, 2008). To this end, below, I summarise my background, theories and assumptions regarding care in the context of older people and my current role as a volunteer with a local carers centre.

My personal and professional care experiences have profoundly impacted the study motivations, the question, and the choices I made concerning the study design, methodology, and analysis. I began this study as a researcher with pre-conceived ideas about what care of older people means and the well-being of carers. My experiences inform these ideas as a formerly paid carer and now caring for my father from a distance who is living with co-morbidities and supporting my mother, who is caring for my grandmother with vascular dementia. During a gap year before my undergraduate degree, I worked as a paid carer in a residential care home for older people and continued working for four years during my studies degree and thereafter. This work left a huge imprint in me, and every stage of this research has been inspired or informed by these experiences and my reflections on them. I was deeply affected by the reality of being a carer for older people. The intimacy of caring and the vulnerability of the care receiver left me feeling overwhelmed and severely underskilled. I found the work incredibly tough but deeply rewarding. It taught me many things about people and families, human vulnerability and humility. I, unfortunately, witnessed examples of 'bad care' and began to think about how 'systems of care' - informed by the broader institutions, values, collective and individual circumstances play a significant part in 'caring outcomes'.

6.7 RESEARCHING AS A VOLUNTEER

As a researcher interested in ageing and older people, I had long-standing connections with the local carers centre. I have volunteered with the carers centre for two years to support the dementia carers coordinator. When the covid-19 pandemic restrictions were first imposed, I worked with the carers centre to establish an online drop-in weekly meeting. Ethical challenges derived from recognising my relational situatedness; as a peer support group participant, volunteer, and researcher. I reflected upon the multiple roles that I had assumed, and for three months, I facilitated group meetings as a volunteer for the charity. I did not talk about my research study directly. However, during this time, I was attentive and listened and contributed to discussion relating to the issues and challenges of care of older people and during Covid-19. I kept a fieldwork journal to reflect on my role as a researcher and volunteer. In addition, I began searching the literature for practical examples of the ethics of care approach to research.

These 'felt' ethical dilemmas led me to explore the value and applicability of the theoretical principles of second-generation ethics of care theorists Tronto (2013) Sevenhuijsen (2003) to my methodology. Increasing attention is turning to exploring the value of an ethics of care theoretical framework to research practice and in context-specific ways (Brannelly & Boulton, 2017; Groot et al., 2019). Barnes et al. (2013) worked with a local voluntary sector organisation to research with care (Barnes, Gahagan, et al., 2013). This work provided a reassuring foothold and a foundation on which to embrace practical care ethics with the carers group. Mruck and Mey (2007) suggest that researchers can be compromised by their affiliation and familiarisation with the area of enquiry (Mruck & Mey, 2007). I acknowledged my relationality with the participants I had previous connections with. These are noted in my fieldwork journal, and I also discussed these issues with the supervisory team. I selected or was drawn into certain aspects of the interview discussions because of my background knowledge of the carer and their context. This, I believe, does not represent a compromise in the data. On the contrary, the genuine concern and empathy for the participant's situation contributed to a connection with the participant that adds depth and to the interview as a process and an event.

During interviews with the participants that reflected upon being drawn into selected certain aspects of follow up questioning in the discussions with carers over other elements, for example, I was interested in the idea of choice and freedom to care because I had an awareness of the unspoken value base on which care is enacted based on duty. I also understood that for many carers, there is no other choice and saw this first-hand through the limited capabilities to choose the conditions on which to care. I set aside these ideas and through this saw that rather than the carers articulating burden and oppression, their comments identified ideas of empowerment, pride, feelings of self-worth and clear understanding of the vital role that they play in society more broadly. I began to articulate this within the idea of caring solidarity that Tronto offers – a caring society is good for democracy. Using a research log to document and reflect on my reflections and changing views as a researcher was paramount. In this log, I could track back to iterations, reflections on the research process, and the results. This process was just as necessary as the reflection itself and helped me reveal my pre-conceived judgements on some of the data.

In sum, I reflected that I could exercise a type of 'research with care' practical ethics of care based upon Tronto's (2013) five aspects of care, which gave deeper insight and understanding to the data.

In the next section, I will outline the methods selected for this study and the specific steps taken, including addressing the study's ethical and practical considerations.

6.8 STUDY METHODS

The research strategy adopted was qualitative. This is particularly suitable as it supports responding to exploratory research questions and, importantly, social 'problems' or the 'crisis of care in the context in which this study is located (Silverman, 2015).

The key feature of critical realism is a presentation of three layers of reality; 1) an empirical domain (a sensory experience), 2) actual (action in events), and 3) real causal powers separate not always presented in empirical and actual (Smith & Elger, 2014). Taking these levels of reality, I selected them based on their suitability in responding to the enquiry at that specific level. This is presented in Table (3) below. This approach is based on Amber Fletcher's recent study of female Canadian rural farmers in which she applied a CR ontological position to develop the 'Iceberg Model' (Fletcher, 2017).

Table 3 Critical Realism Three Main Methods

Methodology	**Method**	**Domain of reality**	**Method selected in this study**
Deduction	A hypothesis of the phenomena	Actual	A Critical review of well-being and care theory
Induction	Observation of the world and phenomena.	Empirical – records and empirical data	Primary data collection in the form of QL semi-structured interviews with family carers Secondary data analysis of findings from a scoping literature review of empirical outcomes

Retroduction/abduction	The unseen causes are shown in their effects and imaging new possibilities	The underlying real domain.	Thematic analysis of interview transcripts informed by the analytical framework

The research design was undertaken in three steps outlined in the table above and incorporated the methodological approaches of critical realism; deduction, induction and retroduction.

Step 1 – Through a process of deduction that involved a critical engagement with the literature, I developed a theory-driven analytical framework. It is noted that Bhaskar affirms the use of deductive hypothesis and theory. Still, it cautions that initial theories facilitate a more profound analysis that can support, elaborate, or deny that theory to help build a new and more accurate explanation of reality. This research was initially guided by feminist ethics of care and capabilities approach to well-being. But, aligned with CR epistemology that all knowledge is fallible, I understood that I might ultimately modify or reject this theoretical framework to explain well-being in the context of care better.

Step 2 – Empirical level. This is defined as the realm of events as we experience them. At this level, events or objects can be measured empirically and are often explained through 'common sense.' Still, these events are always mediated through the filter of human experience and interpretation; social ideas, meanings, decisions, and actions occur and can be causal (Fletcher, 2017). Empirical data findings are provided in this study through semi-structured interviews with carers. In addition, secondary data analysis of empirical data is also offered through the scoping review of empirical outcomes of care on well-being (presented in Chapter 2 – Part 4).

Step 3 - Finally, the third level is the real. Causal structures, or 'causal mechanisms,' exist at this level. These are the inherent properties in an object or structure that act as causal forces to produce events (i.e. those appearing at the empirical level). The processes retroduction and abduction were applied to analyse the 30 interview transcripts.

Primary data was collected through qualitative in-depth, semi-structured interviews. I will now discuss why interviews were selected as the most appropriate data collection method and how the interview schedule was produced, piloted, and associated procedures were undertaken.

6.9 THE RATIONALE FOR USING SEMI-STRUCTURED INTERVIEWS

Semi-structured interviews were selected due to the appropriateness to both the epistemological position and research perspective. They have been extensively used as a research method of data collection. They are broadly understood as a qualitative inquiry method to obtain descriptive data on social processes, values, views, perceptions, and actions (Rubin & Rubin, 2011). In this study, qualitative interviews were also applied to test the conceptual framework developed through the literature reviews and policy analysis. It can be understood to make sense of theoretical concepts and consider their relevance to 'everyday life' (Ward, Ray, & Tanner, 2020, p. 220). Qualitative interviews allowed for exploratory questions and also for explanatory reflections. They can offer deep and insightful accounts relating to meaning and processes (Holstein & Gubrium, 2016). As such, they were selected as particularly suitable for this study. Interviews are acknowledged as a situated experience; "Interviews are unavoidably meaning-making venture." (Gubrium & Holstein, 2001, p. 157). In this way, they can be understood as not reflective of participants' true reality' offering only a partial stage-managed view (Hammersley, 2018). I acknowledged these criticisms but took the view that interviews could provide invaluable insights, particularly in the context of the Covid-19 pandemic. I reflect on this in the section below.

Ethical approval was granted just before the Covid-19 outbreak, and I had arranged for the first interview with a family carer to take place one week before the Covid-19 restrictions were imposed. As a result, all fieldwork interviews were conducted following social distancing restrictions and all in-person interactions were postponed. In terms of project management, conducting interviews online or via telephone represented a convenient and efficient method for engaging in research interviews. In addition, online interviewing has been noted as particularly useful for participants who may be reticent or shy in face-to-face contexts (Silverman, 2015). I was mindful, however, of issues relating to digital exclusion, specifically concerning carers. For example, a recent report by Public Health Wales and the King's Fund (2020) has found inequalities in healthcare due to digital exclusion. The report noted that older people, rural communities, and those in Wales with a low income were most affected by digital exclusion. Groups already subject to disadvantage and worse health outcomes may also be affected by it (Honeyman M, Maguire D, H, & A., 2020).

Reflecting on these issues and the context of Covid-19, where inequalities have been further exacerbated and entrenched, I offered telephone interviews as the primary method. If people were online, I asked which they would prefer. The majority of participants (N=21) requested and therefore participated in the interview online. It is worth noting that the 9 participants who did not participate online did so predominately because they did not access the internet and fitted some of the agreed profiles of most at risk from digital exclusion.

Carrying out the interviews online or by telephone enabled me to practice attentive and active listening. Having carried out face to face interviews in the past, I felt more attentive with little or no background context on which to be distracted or draw upon and infer additional unspoken meaning. In this way, some of the associated problems of interviewing as a method of data collection were avoided

6.10 DEVELOPMENT OF INTERVIEW SCHEDULE

The questionnaire was structured reflecting the results of the literature review findings to identify what aspects of well-being carers identified most readily with. For example, eudaimonic or hedonic ideas of well-being were explored with questions relating to personal growth and pleasure. A semi-structured approach to the interviews enabled a type of standardisation for queries but also elicited a certain amount of freedom and flexibility for additional questions and adjustments to be made during the interview (Bryman & Bell, 2011). A type of open interview format would not be suitable for the study because my position of critical realism assumed more than one layer of reality, and the use of standardised questions allowed for cross-comparison between transcript findings. The interview schedule is provided in Appendix (2). The questions were formulated based on the literature review findings and the policy analysis. They were piloted with three carers before the interview. The schedule was refined based on feedback from participants. This feedback revolved around the abstract and elusive nature of the concept of well-being. As such, I removed broad questions such as 'what is well-being' and replaced them with 'when was the last time you felt well and can you describe this?'.

The research interview was split into two stages: Stage 1) As a way of introducing respondents to the central idea of well-being and gaining initial insights, all respondents were asked to respond to the broad question "what does well-being mean to you as a carer? And/or when was the last time you felt well? Can you describe what this is?" Avoiding the imposition of *a priori* codes, the interviewees were not provided with a frame of reference or any vocabulary relating to the idea of well-being.

Open coding was undertaken at this stage. In the second part of the interview, participants were asked questions relating to the domains of well-being identified in the literature and the conceptual framework put forward by McGregor and Pouw (2016). As discussed in previous chapters, the idea of well-being is broad and disparate, and for this study, a capabilities approach to well-being is adopted. Three broad domains of well-being have been identified through the literature and were used to organise the interview questions and subsequent analysis. This second stage began by exploring the components relating to the carer subjective well-being. However, it is noted that the way I constructed questions within the schedule was unavoidably shaped by my own preconceptions, knowledge, and preconceptions concerning family care.

6.11 STUDY SAMPLE AND SELECTION

The study employed a non-probability sampling technique of purposive sampling, This type of sampling is commonly used in exploratory research (Sarantakos, 2012). However, it is noted that the use of purposive sampling techniques limits its generalisability as the sample is not representative of the population (Becker, Bryman, & Ferguson, 2012). Purposive sampling was aligned to the overall exploratory nature of the study; therefore, generalisability was not a requirement of the data collection. Purposive sampling also requires critical engagement about the parameters of the study population, and thus the selection criteria must be chosen carefully (Silverman, 2015). The selection criteria are discussed below.

The research study aimed to recruit carers involved in all kinds of relationships that involve care or support, and the term carer can mean different things. In line with recent social care legislation in England and Wales, the study defined care and support as something if the person identifies it as such. A family carer can therefore be someone who:

- It provides a pattern or routine of care or support rather than a one-off or very occasional activity, but it doesn't have to be every day, a minimum number of hours per week, or the same number of hours each week.
- There does not have to be a family relationship between the participant and the person they provide care or support to. For example, a participant could be providing care or support to a neighbour or friend.

The inclusion criteria for the study were as follows:

- Can verbally communicate in English
- Lives in the UK and provides that care or support in the UK
- Has provided or provided care for an older family member, neighbour or friend over the age of 55 regularly but is not paid to do so within the past year.
- Participants do not have to live with the person they care for or support.

Carer exclusion criteria

- Only provides care occasionally, e.g. mowing someone's lawn or taking them to the supermarket
- Under the age of 18

I consulted with the literature regarding case numbers in terms of data saturation. Based on the literature and to aim for diversity, I aimed for around 30 interviews with family carers. This number also represented a realistic and feasible number given the study timeframe for fieldwork. (Fusch & Ness, 2015; Ritchie, Lewis, Nicholls, & Ormston, 2013).

6.12 PARTICIPANT INFORMATION

Participants who consented to the interview were sent a pre-interview self-completion questionnaire (Appendix 1) that included basic demographic information. Participant demographics are highlighted in the table below. Postcodes were obtained to inform an analysis by broad indications relating to relative deprivation. The Welsh Index of Multiple Deprivation (WIMD) is the Welsh Government's official measure of relative deprivation for small areas in Wales. It is a National Statistic produced by statisticians at the Welsh Government. WIMD is a measure of multiple deprivations that is both an area-based measure and a measure of relative deprivation. WIMD identifies areas with the highest concentrations of several different types of deprivation[9]. The use of WIMD analysis and collection of participant postcode reflected the study focus on understanding external aspects of carer well-being and the empirical evidence of higher levels of deprivation amongst carers than non-caring population. Including the WIMD also responds to the predominant focus of the carer well-being empirical literature on the individual burden. The WIMD score identified the area level of relative deprivation the participant lived in; however, the WIMD is not intended to identify deprived individuals. In Chapter 5, broad inferences were made relating to carer material resources and carer well-being outcomes. Analysis was not conducted to determine causal relationships between WIMD score and carer self-reported outcomes.

6.13 ETHICAL AND PRACTICAL CONSIDERATIONS

The research study was granted standard ethical approval for conducting semi-structured interviews with family carers (See Appendix 1 for full application). In addition, I adhered to the principles of ethical conduct and good research governance as outlined by Swansea University's Research Integrity Framework and the British Society of Gerontology ethical codes of practice. Several salient ethical and practical issues relating to this study included; the particular circumstances of carrying out data collection with potentially vulnerable adults during a global pandemic. These are reflected upon under section 6.13.1 below. Other

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[9] WIMD is currently made up of eight separate domains (or types) of deprivation. Each domain is compiled from a range of different indicators. The domains included in WIMD 2019 are: a) Income b) Employment c) Health d) Education e) Access to Services f) Housing g) Community Safety h) Physical Environment. WIMD ranks all small areas in Wales from 1 (most deprived) to 1,909 (least deprived). The small areas are otherwise known as Lower Layer Super Output Areas (LSOAs).

important ethical issues related to informed consent, data protection, confidentiality, anonymity and avoidance of risk and harm. I address these in turn below before highlighting the specific ethical procedures undertaken to ensure ethical and good research governance principles were upheld throughout to avoid and minimise harm and risk to all those involved in the study.

6.13.1 Informed Consent, Confidentiality, Anonymity and Privacy

As a volunteer with the local carer's centre, I had prior connections to some of the study participants through my role as a volunteer with a local carer's charity. This raised several ethical issues. Firstly, these relate to questions of informed consent. To obtain informed consent, potential participants should be given any information that a participant might conceivably need to decide whether to participate (Carolyn, 2012) I was very aware of my role as a volunteer and researcher with the carers charity and the need to ensure that participants should be entirely free from any form of coercion and participate in the study with informed consent. Specifically, I wanted to make sure that participants would not agree to participate in the research, to please me as a researcher - a form of the social desirability effect (Bergen & Labonté, 2019). Firstly, I discussed with the charity staff concerns that my role as a volunteer could sway or coerce participants into taking part. These discussions proved very helpful and alleviated concerns regarding coercion, and staff reassured me that the individuals would not feel obliged to participate because of my voluntary role. The team also told me that all clients who accessed their services and group support sessions and who I would contact or meet to gain informed consent would not lack capacity as defined by the Mental Capacity Act.

Furthermore, having worked extensively with older people, including those living with dementia, I felt I had the necessary skills and experience to assess an individual's capacity to give informed consent in this research. Participant information sheets were given to all participants (see Appendix 1). Before conducting the research interview, I gave a verbal overview of the research study and highlighted the issues of confidentiality and anonymity. I was very deliberate in the choice of language used in the participant information sheets and when speaking to participants initially on the phone or online. As a volunteer, I understood the importance of emphasising that the carers were experts in their own lives. I avoided jargon and any patronising or 'professional speak', relayed that there were no right or wrong answers, and encouraged participants to speak freely, reemphasising confidentiality and anonymity. I told participants that they were free to withdraw from the study at any time and that their data would be deleted if they chose to start (one participant requested a withdrawal from the study but did not give reasons why).

Participants were asked to send me via email or post a signed consent form having obtained verbal consent (see Appendix 1). A copy of both the consent form and participant information form was kept by myself and the participant. Nevertheless, I reflected upon and deliberated about whether some of the participants may have felt obligated to participate in the study as a result of my voluntary role. Before commencing the interviews with participants who I had contact with through my voluntary role, I emphasised that I did not want them to feel obligated in any way or obliged. The use of a Participant Information Sheet (Appendix 1) guided these conversations. However, all the participants I had prior connections with indicated their willingness to support and participate in the research. This was captured in the digital voice recording and written form via the consent forms.

Confidentiality and anonymity were reflected upon as vital ethical issues. A unique participant reference number was attributed to each participant at the first stage of the research process (pre-meeting telephone discussion). All participant data (audio and written) was anonymised, and appropriate pseudonyms were applied. Where names and addresses are given (to send out the information sheet and consent form) after the documents have been returned, postal address and name were deleted from the excel spreadsheet. All fieldwork was undertaken during Covid-19 restrictions. All paper records were kept at home locked in a secure cupboard. A researcher fieldwork task list provided a crib sheet or guide to managing the study data and ensuring all data handling was done according to regulations and good practice. All participant identifiable information was removed from any electronic or written correspondence, and any personal information was deleted from verbatim transcripts and audio files. All participants were briefed individually before the audio recording, and verbal and written consent was obtained to record the interview.

6.13.2 Avoidance of Harm and Risk

Ethical approval was granted just before the covid-19 outbreak, and I had arranged for the first interview with a family carer to take place one week before the Covid-19 restrictions were imposed. However, in collaboration with the local carers centre, I decided to cancel the interview before the announcements regarding restricting social movement and avoiding contact with people outside of your household. This reflected the sense of growing unease that carers (that I was in contact with through the carers centre) expressed to me. My personal views were that cancelling all data collection represented the most ethical course of action.

During the interviews, some participants became visibly upset. Ethical protocols relating to these situations were actioned, including offering to finish the interview immediately and an offer of a 'ring back' within 30 minutes to 'check in' and, if appropriate, giving information on local community support groups and help. This protocol was affected two times when I deemed it appropriate to stop the interview because the participant showed signs of distress. After every interview, I reflected upon and engaged with the ethics of care literature relating to 'caring with' (Tronto, 2013). It reinforced the hypothesis that an ethics of care and capability approach to well-being founded upon a concern for social justice can support this study theoretically and in a practical applied way.

6.14 DATA ANALYSIS

An interpretation of the results of 30 interviews with carers of older people is based on the analytical framework presented in Chapter 2 (based on the literature review of theory, policy and empirical impacts of well-being in care). The analysis is both descriptive and normative. Firstly, the descriptive analysis presents the findings described by family carers and draws upon the verbatim transcripts to offer an account of the views and experiences of well-being according to family carers. Repeated patterns of meaning and themes were organised firstly according to the three broad domains identified in the literature chapter (2). These three themes: material, relational, and subjective, were used to organise and 'hold' the data. Then, an iterative process of analysis involved moving back and forth between data - the interview transcripts and literature to identify codes and refine themes.

Later stage analysis moved beyond these broad categories to identify the final themes. This analysis stage involved a normative critical analysis where description of themes was overlaid with the analytical framework that searched for the 'latent meanings' (Braun & Clarke, 2014) of well-being within the context of older age care. The latent stage analysis sought to explore the value base in which well-being conceptualisations are nested. These point to social and political implications and are reflected upon throughout the findings and discussion chapter (see subsequent Chapter 7). The next step was the process of abduction – also known as theoretical retroduction – in which empirical data are re-described using theoretical concepts. Abduction has been defined as a process of 'an inference or thought operation, implying that a phenomenon or event is interpreted from a set of general ideas or concepts' ((Danermark et al., 2019). Abduction raises the level of theoretical engagement beyond a thick description of the empirical entities but acknowledges that the chosen theory is fallible (Fletcher, 2016).

6.14.1 Covid-19 Context

Data collection was conducted during the first Covid-19 lockdown during the spring ad summer of 2020 in Wales. This context represents a particular context that inevitably shaped and influenced both data collection and analysis. In theoretical terms, because of the pandemic, lives were placed under threat and lived under drastically altered circumstances. Furthermore, moral binaries were further entrenched and pronounced: freedom vs safety, health vs wellbeing, deserving (of care) and un-deserving. The coupling of an ethics of care, in combination with a focus on capabilities as the metric of justice, preserved a critical eye for ambivalence, contradiction and attention to the normative value base on which policy responses were developed. These are reflected upon in Chapter 7 - findings.

The practical approach to the interview data analysis was developed using the six steps outlined by ((Braun & Clarke, 2006). A theoretical thematic analysis was undertaken using the broad analytical framework (see Fig 8) informed by the literature that understands care as relational and from an ethics of care perspective and well-being as multidimensional, and a capabilities approach, particularly the framework provided by Yerkes et al. (2019).

The process was reflexive, iterative and nonlinear, involving a constant moving between phases and analysis and involved reflexivity. The process was also cyclical, involving revisiting both literature and research; conceptualising the data involved breaking down the concepts and rebuilding them. Thus analysis involved a constant moving back and forth rather than a stepped process. Throughout the process, I reflected the frame of mind that I was bringing to the analysis (Erickson, 2004) looking for semantic and descriptive meaning.

Table 4 based on (Pritchard, 2020) below outlines the analytical process.

Table 4 - Summary of Analytical Process

Analytical stage	**Summary of analytical process**
1. Familiarisation with the data	I read interview transcripts several times accompanied by memos, notes and initial ideas for codes.
2. Generating initial codes	The data was organised systematically and reduced way reducing the data into subheadings. This was done using both deductive and inductive analysis.
3. Refinement of themes	All codes were sorted and combined, and arranged into potential overarching categories.
4. Reviewing themes	Categories were reviewed at the level of the coded data extracts. This meant ensuring the extracts for each theme formed a coherent pattern. Secondly, the validity of the category was considered in relation to the dataset. This meant ensuring the categories reflected the meanings evident across the whole dataset.
5. Defining and naming categories	A refinement of the categories was undertaken to ensure I understood the overall story of each theme and how these fit together within the overall story of the data.
6. Producing the report	Selected and presented illustrative coherent examples of themes identified on which to tell the story of the data; these should demonstrate the merit and validity of the analysis.

The specific research questions drove the process of identifying the themes: What does well-being mean to carers of older people? What normative assumptions are made about the concept of well-being? What are the implications of this understanding of well-being on family carers? How I measured what is an assumption was determined in several ways: the latent meaning level seeking to identify the underlying meanings, ideas and assumptions that in turn inform and shape how well-being is understood at a semantic level; is informed by the actual meaning; "If she's well then I am well", so well-being was identified as a relational activity? This analysis leads me to the sub-theme of interdependency. Finally, the respondents showed how care is ambivalent through the contradictory responses.

6.14.2 Generating Initial Codes

NVivo software helped organise the data and group the themes and data together. Themes were produced manually. A list of codes was drawn from the literature review findings; however, these codes were changed, eliminated, and supplemented with new codes during the process until every piece of text was coded. Drawing upon Fletcher (2017), I searched for tendencies within the data, broad trends or broken patterns in empirical data. These are understood as 'demi-regularities.' (Fletcher, 2017). The inclusion of an inductive approach at this stage of the analysis was undertaken to allow for as many codes to be identified and to recognise tensions or inconsistencies within and across the data that depart from the theoretical framework presented. (Braun and Clarke, 2006).

6.14.3 Searching for Themes

Codes were reduced and organised into broader themes, and in line with CR informed type categories of 'structure' and 'agency.' Through the process of retroductive analysis retroductive analysis I searched for key causal mechanisms influencing carer well-being. Although carers did not refer directly to vulnerability, I identified this theme as a key causal mechanism in which carer well-being can be understood. An initial thematic map was developed (chapter 7.3).

6.14.4 Refinement of Themes

At the refinement stage, I looked through the interview data again and saw that the theme of positives of care codes was too dominant. I had imposed this too readily responding to the identified knowledge gap relating to care burden theorisation.

6.14.5 Defining and Naming Themes

There is a discussion between the results distinguished by structure and agency within each theme. This reflects the critical realist analysis that seeks to identify aspects of well-being that are not confined to the subjective interpretation of findings but seek to identify the reality or hidden meaning of well-being contingent upon socio-political elements.

6.14.6 Producing the Report

The final themes are presented in Chapter 7 – Results.

6.15 VALIDITY AND RELIABILITY

Notably, the analysis reflected upon and attempted to identify 'deviant cases', these are data examples that challenge the hypothesis or counter the emerging argument based; 'One rationale for a single case is when it represents the critical case in testing a well-formulated theory' (Yin, 2009). Similarly, Liedtka (1992) refers to researchers need to show "an attitude of scepticism, an attention to outliers, rival explanations and negative evidence" (Liedtka, 1992, p. 176). This eye for deviant cases was developed through the stages of analysis.

6.16 STRENGTHS AND LIMITATIONS OF THE METHODOLOGY

The strengths of the selected methodology derive from their suitability to the research question. As outlined, there has been very little research that seeks to connect and explore the meaning of well-being with family carers or that seeks to understand how carers themselves articulate well-being (Cunningham et al., 2018; Keating et al., 2021; McGregor, 2018). In addition, there has been a limited empirical investigation that draws upon qualitative accounts from carers, with the predominance of quantitative empirical data (Cunningham et al., 2018). This represents a significant knowledge gap that this study has responded to. The overall approach of qualitative design is fundamentally well suited. It supports understanding what well-being means for carers and its implications more broadly.

The interview data provide richness and potential for revealing deep complexity, tension and contradiction. Furthermore, qualitative data provides possibilities for understanding latent and underlying issues (Moriarty, 2011). The accounts provided by carers themselves are vivid and powerful, deriving from the direct accounts of care. Therefore, the data can be understood to be vivid and powerful, potentially impactful (Miles & Huberman, 1994). The value of this research also lies in its real-world application both at structural (policy) levels and at an individual level (carer).

The usefulness of qualitative research in policymaking processes has been well documented (Green & Thorogood, 2004). Therefore, a policy analysis was undertaken to complement and develop an understanding of well-being in the context of care. Policy insights based upon these findings are provided in the Conclusion. In addition, participants themselves derived benefits from taking part in the interviews. As a researcher, I was aware of the need to avoid and guard against providing any type of advice or offering therapeutic interventions to participants throughout the interviews. Nevertheless, many of the respondents reflected at the interview close how they enjoyed talking and the time to reflect on themselves and their situation. Furthermore, the fieldwork took place at the beginning of the Covid-19 outbreak, in this context the interviews were understood to provide participants with a time to reflect and take stock during a time of immense and unfathomable experience.

Several carers were unaware of the free local support services that were available. After the formal interview had finished, I was able to signpost them to local service providers (local carers centre and central LA helpline number). In addition, two carers emailed me to tell me that they had received benefits advice that increased monthly income as a result of accessing services. Another carer applied and received additional hours for respite care. Finally, one carer described wanting to 'make a difference’. I sent her further information relating to a local carer's consultation forum, which she subsequently joined and represents carers at the local regional partnership board.

Rossetto (2014) explores the value of qualitative interviews, asking what value can be derived from relational research (Rossetto, 2014). The self-reported benefits that participants described as a result of taking part in the research demonstrate that although the qualitative research interview is not therapy, it can be understood to be therapeutic (op cite). I also noted that the interview represented more than a research practice to the carers. It was a relational interaction that resulted in benefits to the participant, and the obvious benefit derived from providing their detailed and open accounts. This I present as clear strength of this research, particularly given the vulnerably and precarity of the carer's situation during the time of the interviews, which took place at the beginning of the Covid-19 outbreak. I note, however, that I only received responses from participants who informed me of positives they derived from the interview. It could be that participants who didn't experience any positive simply didn't report this to me.

6.17 LIMITATIONS

The research has several limitations. The study findings are based on a relatively small sample size, so they cannot be generalisable. However, it is noted that this research study did not aim to generate a generalisable or universal meaning of well-being in the context of care. Instead, the study was principally concerned with deepening understanding, questioning taken for granted assumptions about concepts and meanings concerning care and exploring the possible implications of these meanings to carers and care of older people. In addition, the nature of qualitative research makes it challenging to generate causal relationships between processes.

Challenges of potential researcher bias is an enduring problem of qualitative social science research more broadly. This can be understood as based upon a positivist ontological world view - that value-free knowledge can be obtained and generated. I agree with Priscilla Alderson that the sociologist's explanatory theories based upon exploration of power relations and inequalities or the 'unseen' factors of social life not verifiable via empirical (positivist) measures must be acknowledged if we are to have any promise of changing damaging or oppressive systems; "The bias in silence and avoidance, which inevitably actively or passively support the powerful groups, is mistaken for neutrality." (Alderson, 2021). My ontological or worldview has been outlined above, explicitly stating which theoretical perspective I base the study's research design and methods on. Aware of this and through the use of research logs and discussion with the supervisory team, I sought to avoid the imposition of bias or prejudice based upon my world view alone but acknowledged my perspective alongside collection and analysis of the empirical data and the theoretical insights provided by the scholarly community including sociologists, feminists and gerontologists.

Finally, the methodological approach of critical realism supports a type of participatory or 'emancipatory practical research' (Carolyn, 2012)). Although I had a background in participatory work, I decided that this study would not exemplify a fully participatory approach. This decision was made based on mainly practical concerns. Firstly, from an ethical perspective, I was aware of the value of ensuring that participation was meaningful, not a 'tick box' form of basic research consultation. The study was not originally written or designed based upon a participatory framework. Thus timescales and budget headings did not reflect or incorporate the necessary resources to support this work. These pragmatic considerations prevented me from implementing a collaborative approach and one that would do justice to those involved and the sentiment and spirit of participatory research.

Nevertheless, and despite this, the research study provided personal benefits to the participants (as outlined above) and responded to a knowledge gap in presenting primary data findings grounded in the experiences and voices of carers during the Covid-19 pandemic. In addition, insights and conclusions have been reported upon and published in two peer-reviewed journals.

6.18 CHAPTER CONCLUSION

This chapter has outlined the ontological and epistemological foundation of the study. I have detailed the methods chosen and justified their selection aligned to the overall research question and objectives. Second, I have outlined the methods and study process and highlighted the study's specific ethical and practical implications. Third, I have described the thematic analysis steps undertaken to identify themes based upon the primary data analysis. Finally, I have described issues relating to the study reliability and data validity.

The next chapter presents the original findings based on the study's primary data collection of 30 semi-structured interviews and outlines the key themes based on the thematic analysis of interview transcripts.

7. CHAPTER SEVEN – PRIMARY DATA FINDINGS AND DISCUSSION

7.1 INTRODUCTION

In this current chapter, I present my qualitative analysis of the primary data collected in this study. The data is based upon analysis of thirty semi-structured interview transcripts from family carers of older people. I relate the analysis specifically to the key findings of the literature and policy review. These are summarised below:

1. Carer well-being is theorised primarily based upon an implicit or under problematised burden and stress discourse
2. The burden discourse obscures the broader normativity of care
3. Carer well-being is predominantly measured through subjective scales
4. There is a gap in knowledge regarding how well-being outcomes operate across and within relational contexts, including socio-political and cultural levels
5. There is relatively little knowledge that captures carers' views on how care influences and affects their ability 'to be and to do' what they most value.

Furthermore, the data analysis aimed to address and respond to the findings above and the overall research study aim and purpose. The analysis focuses on how carer well-being is understood based on the self-reported accounts of this study participants and, in particular, the role and influence of extrinsic cultural and socio-political factors. It is important to note that the analysis did not seek to identify a fixed position, statement, or definition of well-being within care; instead, the aim is to use the analytical framework to provide an exploration to critically engage with the concept of well-being in the context of care.

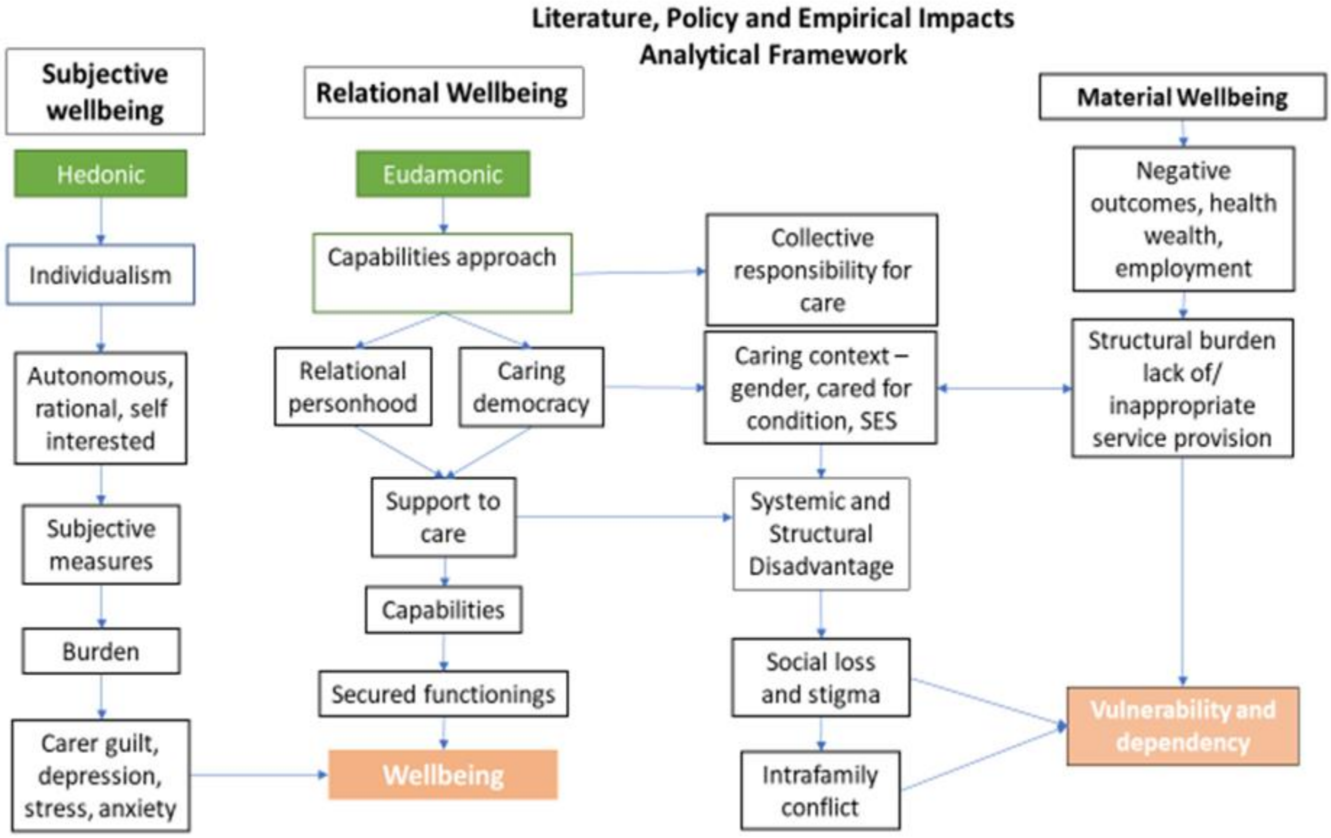
7.2 STRUCTURE OF CHAPTER

This chapter is structured using three major headings identified as key themes identified through the thematic analysis. These findings provide empirical and theoretical insights relating to the meaning and implications of well-being in the context of care and are described and reflected upon in detail. Final concluding statements and insights are provided in the subsequent chapter (Conclusion).

7.3 ANALYSIS AND INTRODUCTION TO THEMES

The analytical framework developed in Chapter 2 – 5 presented below informed the analysis. The analytical procedures followed the six-step thematic analysis Braun and Clarke (2006) outlined and detailed in the previous chapter Methodology (Chapter 3). The thematic analysis sought meaning at the latent and interpretive levels.

Figure 9 - Analytical Framework



Themes were identified through a coding process that was reduced and organised into broader themes. An initial thematic map was developed; see below Fig 12 below.

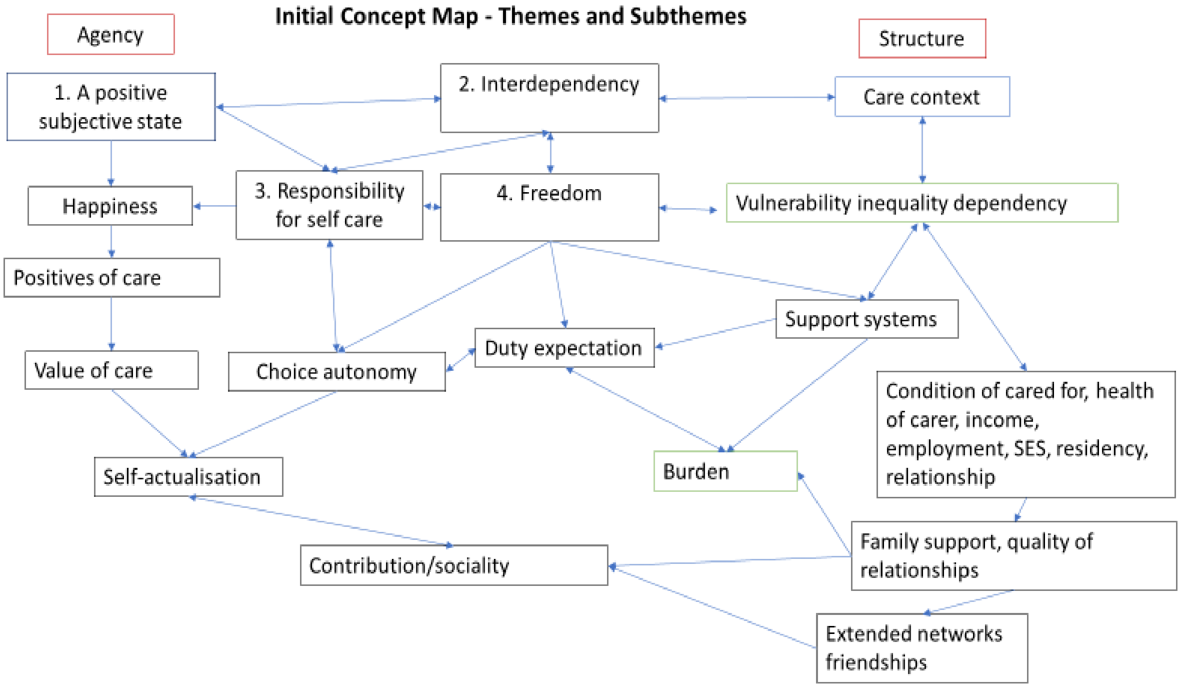


Figure 10 - Initial Concept Map

Further refinement of themes resulted in the final identification of three major themes provided in Fig 13 below.

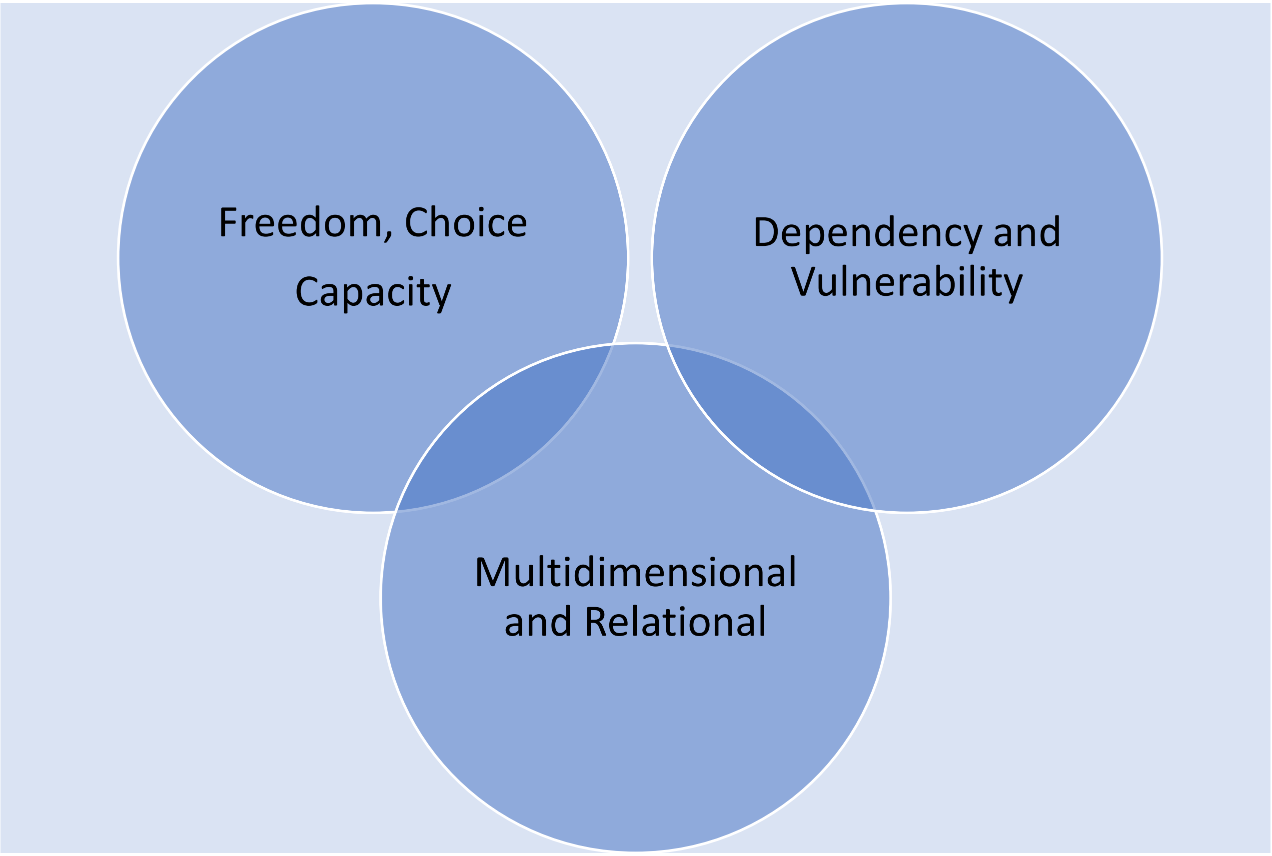


Figure 11 - Findings Final Themes

The major three themes are identified and described below, and several subthemes are provided within each of the three themes and are discussed in detail in the following section.

1. **A multidimensional conception of well-being –** understood as a positive state connected to ideas of happiness self-actualisation and related to the well-being of the cared for and to the caring context.
2. **Freedom and choice** - The conditions/conversions on which to care and to be able to do and to be.
3. **Dependency and vulnerability** – The outcomes of caring are situated within systems dependency and the broader carer context.

Table 5 - Findings themes and subthemes

	Means **(Policy)** **Theme 1** **Multidimensional and Relational**	***Conversions*** **(Sociopolitical context)** **Theme 2** **Freedom, Choice and Capacity**	***Observed secure functionings*** **(Outcomes)** **Theme 3 – Dependency and Vulnerability**
Sub-theme	Happiness and growth Sociality	Freedom	Vulnerability - isolation
	Interdependence	Choice and conditions	Vulnerability intrafamily conflict
	Unhappiness	Expectation to care	Vulnerability - income
	Responsibility for self-care	Lack of alternatives for good care	Dependency on support services
	Positive value and Sociality		

As detailed in Chapter 6 - Qualitative semi-structured interviews were carried out with thirty carers of older people in Wales from April to October 2020.
An overview of the sample is provided below:

- The average age was 55 years
- The gender make up was majority female N= 23 male N= 8
- A high proportion was relatively affluent according to the area based Welsh Index of Multiple Deprivation (WIMD) score. N=19 living in the regions that score seven or higher in WIMD
- The majority were adult child carers N=22
- The majority received care support packages N=16
- Majority providing care to an older person with cognitive impairment or dementia N=22

Table 6 - Participant Demographics

NAME	**Age**	**Gender**	**WIMD rank decile (1 lowest 10 highest)**	**Employment Status**	**Relationship to the care receiver**	**Receiving care support package**	**Condition of person cared for**
MARY	57	F	9	Employed P/T	Adult child	Y	Dementia
ANNA	50	F	10	Employed P/T	Adult child	Y	Dementia
CARMEN	38	F	10	Unemployed	Adult child	N	Dementia
BETHAN	24	F	10	Unemployed	Grandchild	Y	Dementia
CERI	47	F	10	Employed F/T	Adult child	Y	Dementia
ALAN	41	M	10	Unemployed	Adult child	N	Dementia
FLO	51	F	10	Employed F/T	Adult child	Y	Dementia
GERALDINE	54	F	10	Employed P/T	Mother-in-law	N	Dementia
HANNAH	61	F	9	Employed P/T	Adult child	Y	Dementia
ROSE	63	F	6	Unemployed	Adult child	N	Arterial Fibrosis Diabetes
JOANNA	51	F	10	Employed F/T	Adult child	Y	Dementia
KATHLEEN	56	F	5	Employed P/T	Adult child	Y	Dementia
LORNA	62	F	7	Employed P/T	Adult child	Y	Frailty heart condition
DELYTH	67	F	2	Retired	Adult child	N	Dementia
CADI	41	F	6	Employed F/T	Adult child	N	Sight and hearing loss
GRUFF	73	M	4	Retired	Adult child	N	Dementia
ANGHARAD	54	F	4	Employed F/T	Father - in - law	Y	Dementia
ELLEN	78	F	9	Retired	Spouse	N	Parkinson's Disease
ALED	46	M	10	Employed P/T	Adult child	Y	Dementia
CERYS	63	F	7	Employed P/T	Adult child	N	Cancer
CHRISTINE	63	F	7	Employed F/T	Adult child	N	Dementia
CARWYN	89	M	5	Retired	Spouse	Y	Osteoporosis Dementia
LENA	66	F	1	Retired	Spouse	Y	Spondylosis

EMILY	64	F	7	Retired	Adult child	Y	Dementia
JAMES	83	M	8	Retired	Spouse	N	Dementia
RHIAN	61	F	9	Employed P/T	Adult child	N	Heart Failure
IVY	61	F	2	Retired and volunteer	Adult child	Y	Sensory loss
TRYSTAN	77	M	2	Retired	Spouse	N	COPD and Stroke
NOA	58	M	3	Unemployed and volunteer	Adult child	N	Dementia
OSIAN	56	M	1	Unemployed and volunteer	Adult child	Y	Dementia

7.4 THEME ONE – A MULTIDIMENSIONAL AND RELATIONAL UNDERSTANDING OF WELL-BEING

The subthemes of well-being as multidimensional and relational are listed below and will be discussed in further detail in the following section.

Well-being is Multidimensional and Relational
Happiness and growth
Interdependence
Unhappiness
Responsibility for self-care
Value of care and Sociality

This theme was identified through the capabilities approach well-being framework relating to 'means,' which refers to social (policy-driven) and economic resources to which individuals have access and capabilities to achieve valued functioning's can be met (Yerkes et al.2019). Findings show that participants overwhelmingly characterised the broad notion of well-being regarding happiness in keeping with the literature and policy articulations (in the UK). Additional insights, however, find that participants connect the idea of their well-being to the well-being of the cared for. Furthermore, the relatedness of carer well-being requires understanding the caring context, which can exasperate adverse well-being outcomes. Finally, carers identified with a broader conceptualisation of well-being - ideas of doing good and contributing beyond an individual state but are part of what can be understood as sociality.

7.4.1 Multidimensional

This first theme identified derives from the broad questions; "What does well-being mean to you" or "when was the last time you felt well? Can you describe what that is"? Some of the interviewees responded in detail and with clarity. Others were less clear in their responses or offered answers based on their direct experience; "*We just get on with it sort of thing, I'm doing alright she's got her sister with her at the moment, so that's a little break for me.*" (TRYSTAN, 77). Most respondents described well-being as related to subjective states, specifically to the absence of negative emotional states; "I think that well-being is about not having that worry I suppose and having people to turn to when you need them" (LORNA, 62). Furthermore, carers pointed to the multifaceted nature of well-being, speaking of both physical and mental health domains: "*It's a holistic state, well-being – it's very difficult to pin it down."* (PO3). *"Physically, I feel quite well most of the time, but emotionally I think I am sensitive quite often. I haven't got clinical depression. I experience anxiety, but I don't want it to cause me deep upset. I mean, I've got other issues going on as well."* (MARY, 57).

7.4.2 Happiness and Growth

"To feel that you're growing." Exploring what well-being means amongst participants about positive subjective accounts provided some rich and detailed data. Amongst the respondent's, happiness was overwhelmingly associated with well-being; *"I Just think that I have to keep my happiness up there, because that almost becomes a job in itself."* (BETHAN, 24). Furthermore, most reflected upon their positive subjective well-being as being highly dependent upon the care receiver and vice versa; "*If I if I'm not happy and well then she's not going to be happy and OK in a sense."* (JOANNA, 51). Many described an account of well-being related to notions of self-actualisation; *"What it means for me to feel well, is to feel in my body as my own identity, not performing a role which is external to myself, to my own trajectory as a human being trying to be self-reliant, self-realised, self-actualised, and a contributor to society. Most of those things have been undermined by my caring role."* (ROSE, 63).

The idea of growth and care as a contribution to personal growth was identified in Chapter 5.3.2. Studies were reported upon demonstrating the positive impacts that care can bring in subjective well-being (Shim et al., 2013). This respondent quoted below felt that not only was this fundamental to her well-being but was also something that should be upheld as an individual right or entitlement; *"It's a human right if we all are entitled to pursue our own self-actualisation, our own well-being, our own ability to flourish & thrive as human beings, well that's certainly is not something that I feel able to do in this role most definitely not.*" (ROSE, 63). Clear connections can be made in this extract to the arguments based on the literature review findings that care can be understood as an essential condition and need of individuals.

Another participant furnished the idea of self-actualisation as the ability to experience personal growth; *"But just having the freedom to be able to move and do opportunities to feel that you're growing in your life instead of in this kind of routine every day caring situation. That's how I'd describe well-being, that you feel healthy, but you also feel like you're progressing in something that matters to you."* (BETHAN, 24). The participant quoted here, is the youngest of the sample and cares full-time for a grandparent. Some interviewees pointed to this idea of personal identity and growth as being curtailed because of care; *"Self-identity has gone, and this is an important part of feeling well…I'm a carer, I'm 24 hours on duty, but I'm not 24 hours physically, I do have a good night's sleep & I can go for walks & I go to the shops & I can have time off to work, but I've got a little bit lost amongst it all."* (Ceri, 47).

The analysis demonstrates alignment with the Aristolean eudaimonic understanding of well-being referred to in Chapter 2.5. This describes happiness as more than the experience of pleasure and as something relating to self-actualisation and personal growth and connected to sociality and is expanded upon further in this section below.

7.4.3 Interdependence

"I'm the jam in the sandwich." (MARY, 57). The theme of interdependence was identified through the analysis, with many respondents referring to or assuming a connection between their well-being and the person cared for; "I am the jam in the sandwich, if I go, we all go." (MARY, 57).

> *"What is my definition of well-being? I think because we're talking about two people as carers, I mean in this situation. It's when both people are happy and have a feeling of well-being. I don't think it just depends on me because if the other person's not well, then I would feel guilty to have a feeling of well-being in a sense."* (DELYTH, 67).

For some participants, the fundamentally relational nature of their well-being was referred to with detailed accounts; *"So we are bonded, we are kind of, there is this conjoined relationship which I don't think is actually what either of us bargained for."* (ROSE, 63). This respondent described how she gave up a life working abroad to care for a parent. Similar respondents described sacrifices made because of care, with respondents not only reflecting the idea of interdependence but also the intensity of the bond of caring, which many participants described in negative terms, and how their own wellbeing is sacrificed to preserve and nurture the cared for; "*But my well-being, I've just had to numb myself to my being in the beginning & over the last few months, I've had to just numb & get on with it & not think about me & what will I do?"* (JOANNA, 51). This can be understood to reflect care as a kind of 'natural self-sacrifice' that is theorised and argued by care ethicist Virginia Held (1995) and is understood by care ethicists to form a prevailing norm and a natural justification for family care and according to some authors, validation for withdrawal of state support for care (Held, 1995; Tronto, 2013).

By exploring the idea of interdependency as an attribute of carer well-being, the physical condition of the cared-for was frequently referred to as a specific variable and mediator influencing both the carer and the cared-for reported states of well-being. For example, in the sample of participants caring for conditions such as dementia, this was referred to as in constant flux; "*I think something like your well-being because of dementia, it's never stable."* (FLO, 51). Another participant referred to frequent hospital stays caused by the cared-for frailty condition and frequent falls; *"It's physically exhausting, it's mentally tiring as well because he's very demoralised to be in the position he was in, so it really has an impact on everybody's life really when they're unwell but anyway we're getting there, we're getting there."* (LORNA, 62).

The idea of a co-dependence between the carer and the care receiver is echoed in the academic literature. As described in Chapter 5.3 studies find a correlation between the care-receiver's clinical diagnosis and the subjective well-being scores of caregivers (Pinquart and Sorensen, 2003). The broad caring context, including conditions, age, gender, SES, informs and influences well-being outcomes. I suggest that the ethics of care approach allows for an understanding of the relational situatedness of the nature of care and offers opportunities to focus on the caring situation and the impact that different aspects of the caring context can make on the carer's well-being. Tension can be identified, however, in that the carers identify their well-being as measured and ultimately reduced to happiness but also understand their well-being as contingent upon the well-being of the cared-for care - a state described by many, as in flux and dependent upon the condition and context of the caring situation. Based upon the carer's self-reported framing of 'well-being as happiness,' this can be understood to be stymied by the existence of the relational nature of care, theorised and presented in this discussion under 'interdependence.' Sevenhuijsen (2003) elucidates this tension between individualism and relationality regarding the enduring norm of 'independent citizenship,' a value base on which care policy is enacted. Although, as described, the carers of this study understand their well-being as dependent upon the caring context and deeply connected to the well-being of the cared for. This makes evident the interdependence of individuals and, as discussed, stands as a direct affront to the idea that people are or should be understood as independent or autonomous individuals (Tronto, 1993). Therefore, the idea of well-being as happiness concerning care is problematic, relying on superficiality and a narrow view of well-being. Importantly for this discussion, I argue further deepens the individualism of care (described in Chapter 3.9). It reflects those who do not experience happiness (well-being) as almost failed in their pursuit and responsibilities, an idea I return to later in the section below.

7.4.4 Unhappiness

A key subtheme identified concerning happiness was the concept of unhappiness and sadness. The majority of carers referred to a 'weight of responsibility' causing stress and negative subjective well-being states; *"From the moment she gets up to the moment she goes to bed she needs somebody here."* (RHIAN, 61). Relatedly, many carers described caring for significant lengths of time and explained the time spent caring as an additional negative aspect to their subjective well-being. This male spousal carer refers to caring for his wife for over 22 years; "*She had a nasty blow to the head about 22 years ago & it all started there. I had to take more care of her & look after her & be careful of anything that she did."* (TRYSTAN, 77). Many referred to the weight of responsibility in terms of the breadth and extent of the tasks involved in care; *"The responsibility as well, it's not just caring for the person it's caring for their life, it's caring for the bills, it's caring for the house so there's a huge load of responsibility & the feeling of responsibility wherever you go it kind of goes with you*"

(ANGHARAD, 54). The carer referred to here described the weight of responsibility she felt caring for a parent in law and working full time. Moreover, caring tasks were frequently equated to paid work, this carer described how she condensed her full time hours into four days so that she can visit and care for a parent; *"I work four days a week, on the Friday I can spend the day, all day with my mother so ..so it's organising everything around that because it's like sort of like working full-time basically so on that extra day, but I love doing it, but it is quite tiring."* (LORNA, 62).

The findings suggest that participants overwhelmingly conflated the broad meaning of well-being with happiness and a positive well-being state. As described in the literature, subjective well-being is a dominant feature of the empirical literature on family carer well-being. It is usually explored based upon the 'unhappiness' experienced by carers. Through a critical engagement with the well-being literature, it was argued that happiness scores are insufficient in theorising carer well-being as they are reductive and obscure systemic differences in well-being outcomes for different groups of people come about and are reproduced (McGregor, 2018). These adverse well-being outcomes are assigned as personal failure or responsibility, as happiness is subjective. Concerning carers of this study, most participants described negative subjective well-being states attributed to their caring role. This is consistent with the literature surveyed in Chapter 5; *"There wasn't any balance, it was just, no, I was fire-fighting really you know. Just constantly having to go up my mother's sort of every day, working, going there straight from work & then coming home here & then maybe finding my husband on the floor collapsed."* (GERALDINE, 54). Many also described feeling overwhelmed and unable to strike a balance in maintaining their own mental and physical well-being; *"Because of her illness mentally she was so nasty & she was accusing my husband of stealing & it was just awful, absolutely awful. Mentally, it just – I wanted her to die, I was glad, I was waiting; honestly, I can't it's just the truth I wanted to be ill myself, I wanted to become ill myself, so I didn't have to put up with it any longer, I couldn't cope, it was awful."* (CHRISTINE, 63).

Negative subjective well-being states were exasperated by the particular context of the Covid-19 pandemic. In Wales (as elsewhere across Europe) blanket restrictions were applied by government and home was deemed the safest place to be. Respondents described staying indoors complying with government directives and the impact on their wellbeing. The majority of carers interviewed in this study were co-resident with the person cared for. The qualitative descriptions provided by participants evidence levels of increased depression and general low mood thus negative impact on levels of subjective wellbeing; one respondent described staying in every day with the care recipient; “I know now this afternoon it’s going to be down,” (IVY, 61). In addition, carers described anxiety and worry regarding the virus and the potential of it coming into the home and reaching their loved on; “So I stay in, I don’t go out. It would have to be an emergency for me to go out”. (JAMES, 83).

Of the respondents who were not co-residing with the person cared for, a related theme emerged of ‘connections lost’. Carers described a sense of disconnect with the person that they cared for impacting on their relationships. In the following example the cared for was living in a care home and the carer describes her loss in terms of not being able to express and connect with her as she usually would through the clothes she wore when visiting; “I had a very good relationship with [cared for] & she loved anything that was bling or leopard skin or anything like that, sparkle, so I’d always go dressed up in something like that – these are my earrings I wear…she’d say I love your earrings because they’re sparkly and we’d chat.” (LENA, 66). Some participants referred to strained relationships because of social distancing; “I’d always give my dad a kiss on his head every time I left him I’d always give him a kiss but obviously I haven’t done that since March. I’m the apple of his eye so just little things like that have been quite difficult as well really. Just to give him a kiss top of his head & he’s happy then for the day.” (HANNAH, 61).

Exploring this theme further and applying the idea of relationality, the analysis looked at how the particularities of caring for a family member who has a lifelong limiting condition. One carer compared caring for her older mother to caring for her young grandchild; *“I know now this afternoon when I’m going to go to my [cared for] & I know it’s going to be down…this is like waiting for the end rather than like [refers to caring for grandchild] is the beginning of this life & it’s fun & you don’t mind the work, it’s just the negativity I suppose.”* (EMILY, 64). Carers referred to dealing with complex conditions that harmed their well-being, *“Emotionally, again, it’s so hard because there’s no happy ending with something like dementia.”* (KATHLEEN, 56). Many carers described feelings of entrapment and claustrophobia, and two referred to acute depressive symptoms, and one described suicidal thoughts;

> *“It’s not just the physical thing of being there with my mother & doing it, it’s that level of patience that you’ve got to be able to sit there & have another very loud Midsummer Murders on the telly in front of you, constantly…There’s very little joy in sitting there with my mother & I think that’s what affects you mentally. I come home exhausted. It’s not because we’re grafting, we’re not doing hard work, but it’s draining on you mentally to be there; it’s very, very hard. (IVY, 61).*

Aligned with the empirical impacts identified in Chapter 5.4, additional negative psychological states referred to frequently were anger and guilt (Gallego-Alberto, 2020). Participants described as compounding overall harmful levels of subjective well-being; *“She would put the burden on me to do it & frankly I’d be really pissed off so I’d be really angry & then I’d feel guilty for myself about being angry for trying to do what my mum’s wishes are.”* (ALAN, 41).” Guilt was often described as caused by not spending time with the cared for or feeling like they are not doing enough for them; *“I think I felt guilty if that’s anything. I felt guilty I couldn’t spend more time with her.”* (CADI, 41). This guilt often translated into blaming themselves for incidents or ailments of the cared-for; *“My mum won’t go for her blood tests, but I’m thinking if I did more to try & get her to the hospital or to get to her appointments, I’m thinking maybe she wouldn’t have this, does that makes sense? I kind of blame myself for the fact that she’s got this condition* (CARMEN, 38).

A further negative subjective well-being state referred to frequently in the analysis was worrying about the future and a lack of control; *“The worry is if either of them declines, or decline suddenly.”* (FLO, 51). *“Yes, the what-if’s? The what-if’s? I follow this Instagram thing, it’s anxiety, well-being… how many what-if’s you need for a nervous breakdown.”* (CERI, 47). This lack of control caused much significant anxiety; *“I’ve got my mobile phone constantly by my side wherever I am, it’s never switched off, or it’s horrendous when the phone rings in the middle of the night & I’m like oh my gosh what’s happening now & is this is, is this the last time there that we’ll see him & things like that so you’re always on edge.”* (HANNAH, 61).

Exploring this idea further during the interviews and, in relation to caring for an older person, carers referred to negative subjective well-being states related to witnessing the deterioration and decline of the cared-for, attributing this downward trend to feelings of depression and burden. Following this line of enquiry, some carers described a sort of inevitability that was caring for someone with limiting life conditions, with many referring to a certainty of frailty and vulnerability and expressed frustration towards what they perceived as a propensity to 'gloss over' what is essentially negative and declining health conditions that make it very difficult as a carer to live with:

> *"It's just stress at my mum's condition; it's appalling to see her just losing bits of herself. I am not able to kind of put that happy face on it that some people are sometimes, just pretend that things are not the way they are, there is no happy ending. I can't pretend there's anything fun about Alzheimer's; it feels like there's a bit of a campaign to kind of cuddly-ise it & make it 'living well with dementia' & I know that's possible, but once people get past a certain point it's just grim. Grim for them, grim for you watching it and having to be part of that."* (ANNA, 50)

The extract below illustrates an inevitable feeling of sadness described by the participant caring for someone living with dementia, but instead of something to feel burdened by the carer reflects that it is something that shouldn't be avoided.

> *"Sadness isn't something to run away from, sometimes you actually have to sit with it you can't just get rid of it, again that sort of positive-negative, sadness is negative therefore you must replace it with positive emotion. Umm no, we can't do that, she's got dementia, she is still going through it, I will be sad about that until she dies & for probably quite a long time after that as well."* (OSIAN, 56)

A further respondent who cared for her father, who had recently passed away and who is now caring for her mother, described a sense of release when the cared-for passed away and after the funeral; *"We were glad when he died because it was such a relief that he wasn't in that position anymore so all the grieving was done before so I suppose when he died then & we got the funeral done I suppose I had a sense of well-being then because I didn't have to worry about him anymore."* (LORNA, 62). These extracts together are essential for this discussion. They show well-being as understood primarily through a prism of positivity or ‘happiness’ results in a reductive or narrow view of well-being in the context of care and particularly care of older people. As illustrated in the above extracts, caring for someone with dementia and/or frailty or with limiting long term health conditions requires a more nuanced account of well-being, one that isn’t confined or limited to ‘happiness’ and that recognises decline and dependency as part of articulations of living a good life or well-being.

As outlined in Chapter 3.10, well-being concerning older people and care is nested within a broader dominant discourse of ‘active, successful or positive ageing.’ The carers of this study antithetically report happiness and sadness. They are reflected upon as bringing negative subjective well-being states. Still, respondents also understood this inevitability of decline as embodied within the ‘care’ of an older person and not something to be hidden, ignored or evaded. This finding can be understood as challenging the invisibility of care for older people and association to the active ageing discourse, ‘well-being as happiness’ more broadly and care for older people and its association to ‘dirty work’ (Clarke & Ravenswood, 2019).

7.4.5 Responsibility for ‘Self-Care’

Overwhelmingly, as noted above, the notion of well-being was associated with ‘happiness’ and ‘interdependence’. An additional related subtheme was identified as the concept of ‘responsibility for self-care, and the majority of carers of this study associated well-being with ‘self-care’. This idea of self-care was identified in the literature under Chapter 3.9. This is also described in the policy analysis, where carer well-being is conceived of as independent of the cared-for and support services are positioned to achieve well-being as an autonomous outcome. Respondents associated ideas of ‘looking after yourself’ with activities such as mindfulness practices and relaxation, exercising, eating well and keeping calm;

> *“I think generally day to day I’m pretty good, I do try & make an effort, I go running, I normally swim, but because of lockdown, there are issues with the pool, so I’ve been running. I do try to look after my own kind of mental health & my well-being & am very aware that it’s within my control so when I do have those moments that I’m not feeling so good or so calm about it I am quite strict with myself & I say to myself come on now, get a grip, let’s go for a walk or let’s go for a run or let’s do something different not to think about it.”* (FLO, 51)

Self-care is understood as an autonomous outcome, and further exploration of this subtheme highlighted that carers associated a personal responsibility for self-care and broader ideas of well-being. It follows that the responsibility for well-being lies with the individual, which reveals a tension with the aforementioned identification of well-being as interdependency. The majority of respondents assumed a sense of individual responsibility unquestioningly for self-care; *"You know it's a balancing act, and you also are responsible for your positive well-being too, so you have to think what I can do right now that's going to make me feel better? Turn the radio up, have a dance."* (ROSE, 63). As illustrated in the two extracts below, a minority of respondents, however, did reflect upon the idea of 'self-care' and well-being with scepticism; *"I think because we talk about wellness, the five ways to well-being and all that stuff but I think until push comes to shove it's all a little bit abstract"* (CHRISTINE, 63).

A further articulation of this scepticism towards self-care and well-being is provided below by the participant, a 66-year-old woman caring for her husband who has various chronic health conditions and restricted mobility. She is active in local carer community groups and has recently completed what she refers to as a 'Carers mindfulness and relaxation' course. She responds to the broad questions relating to the meaning of well-being; *"Well-being? We've been doing many of these Zoom courses with [carer support groups] on what well-being means, and none of it gels. We've been doing a lot of mindfulness and a lot of relaxation techniques, but it's all a bit pointless."* (LENA, 66). The respondent goes on to describe a 'typical' everyday caring situation; a day out in town with the cared for and how despite attending the relaxation and mindfulness technique courses, she refers to these courses as having made a little impact or help in mitigating the stress caused by the situation described below:

> *By the time we'd got into the shop, he couldn't walk again, so …it was the stress, I was literally suffering from a panic attack I know I was & I don't have them often but I was getting so stressed. He was stressed. By the time we got him home he went back to bed. He slept until about 8 o'clock last night, got up for an hour or two & went back to bed about quarter to 10, he's still in bed & he's shaking. So well-being I don't know, it's all a bit of a nonsense genuinely, I would like not to feel stressed or like not to be worried*. (LENA, 66)

Well-being is broadly understood amongst participants as being attributed to enhancing your happiness. An implicit normativity frames this idea of happiness articulated as individual responsibility identified within the findings. But as described in the case above, the carer's well-being or lack of well-being is defined as directly affected by the cared for. Many respondents described daily struggles, difficult circumstances and ongoing stress because of their caring responsibilities (and multiplied for some, particularly in the context of Covid-19 (Masterson-Algar, Allen, Hyde, Keating, & Windle, 2021). Understood in this way, carers can be seen to have a type of limiting control or reduced capacity for self-determination or self-care. Ward (2015) talks extensively of the ideology of self-care in relation to UK welfare reform and argues that the construction of care as individual responsibility of the self exasperates existing inequalities by obscuring the collective responsibility of the state to provide care (Ward, 2015). Drawing upon these accounts and based upon the sub-theme of 'self-care', it is suggested that self-care is often undermined by the demands and nature of the caring role. In many ways, it can be understood to compound adverse well-being outcomes and vindicate government from providing support to carers.

As described above, the ability to look after yourself rests upon the idea of autonomy and self-determination, ideas that care ethicists have challenged as resting upon the enduring norm of citizens as male, rational and autonomous (Sevenhuijsen, 1998a). The implications for carers are that this norm denies relationality and inequalities created by the caring situation itself. The literature points to care as having a range of negative impacts across all well-being domains (Bauer & Sousa-poza, 2015). Concerning physical health, participants described health conditions as caused by or exasperated by caring role, and this is congruent with the literature on carer outcome on health carers described experiencing chronic health conditions, often identifying the mental stress caused by caring responsibilities;

> *"I am not the same person that I was. In terms of physical health, I have had more illnesses in the last 11 years than I've had in my entire life put together & not all of them – they are all stress-related & that has been documented over & over again with trips to the doctor, you're just pressurised & stressed & strained"* (ELLEN, 78).

Three participants described chronic, life-threatening illnesses; *“I also have a disability myself, I’ve got a progressive lung disease which is incurable, so I do tend to get quite sick with that & am aware that my level of anxiety does impact on that so when it all started kicking off with mum & dad I did go into this cycle of being very unwell so my number of infections increased.”* (KATHLEEN, 56). Some carers described their health conditions exacerbated by the stress of care; *“I got diagnosed with cancer, I got diagnosed with a heart condition, it’s really been a whirlwind so managing all of that..but also around the caring thing that you’ve got going on as well so stress we know it manifests physically for me but trying to manage that at times has been quite challenging”.* (ALAN, 41).

Further subthemes relating to health and ability to ‘looking after oneself’ were found linked to not eating properly; *“I think probably a lot of carers probably do neglect or miss it out because they’re so busy but to keep that as a routine then that helps us – it helps me. Times may change slightly, but still I eat around regular times*.” (ALAN, 41). These findings align with empirical outcomes of care identified in Chapter 5.5.4. In addition, several carers reported back injury from care; “*What happened then it was my own fault, it was lifting my dad that my back started, I was lifting some stones & then I fell on the floor and my husband’s shoulder has gone from lifting my dad & of course it needs the 2 of us helping pick him up & everything as well.”* (RHIAN, 61). Another carer described chronic back pain; *“There’s not a lot I can do about it, I’m just in a lot of pain & it means I can’t bend any more which means housework like I can hear my mother saying you’re skirting boards are filthy kind of thing. I can’t pick anything up if I drop it, so I use one of those little stick things. I think caring has not helped.”* (LENA, 66). One carer referred to her health as at particular risk when the cared-for has frequent falls. The carer described several occasions when she had to wait for over five hours for ambulance services to attend and lift him. This carer described increased anxiety and trauma because of these incidents, and expressed anger and noted, *“Why is it assumed that I am not at risk? Why can’t somebody help us sooner?”* (ELLEN, 78). Drawing upon the capability approach to well-being and the idea of secure functionings and risk put forward by Wolf and De-Shalit (2007) and based upon Sen’s foundational work (see Chapter 2.12), we can see evidence of carers experiencing and reporting objectively measurable serious risks and vulnerability to ill health and these are explored further below.

Several respondents referred to sleep deprivation; one respondent described going without sleep for two days because of a crisis; *"Yes, that's happened quite a few times not sleeping like that for two days, yes. It can be very tiring as well really with that then, just feeling continuously tired sometimes & it's on your mind all the time really."(*CHRISTINE, 63). Some carers did not note any adverse physical or mental effects at first; in this following extract, a male carer, when asked if care affected his health, replied, "No, it hasn't affected my health. *Well I don't sleep very good because I've got trouble with my hip & what I do I take painkilling tablets to sleep but apart from that I'm fine I can't go into hospital. No, and I'm surviving, so that's all that matters, and my wife is ok".* (CARWYN, 89). This response suggests that carers often do not attend to or recognise their ailments or respond to their health problems because of their need to care. It is suggested confounded by the little alternatives available to family care.

Through the sub-theme of 'looking after yourself' identified concerning descriptors of well-being, carers described severe health conditions that they identified as triggered and exasperated by the stress associated with care, leaving them at significant risk. However, the extent to which and capacity that carers have to be able 'to look after yourself' is questioned by the findings above.

In sum, and based on the analysis of these extracts, well-being is broadly understood as attributed to an enhancement of your happiness, and there is an implicit normativity framing this idea of happiness articulated as individual responsibility identified within the findings. But as described in the case above, the carer's well-being or lack of well-being is understood as directly affected by the cared-for – articulated in this analysis as the relational nature of well-being and includes the influence of the cared-for condition. Drawing upon these accounts, I argue that 'self-care' in the care context is of limited use and is often undermined by the caring role's demands and nature. The idea of 'self-care' can also be understood to be compound negative well-being outcomes through vindicating government responsibility to provide care support.

7.4.6 The Positive Value of Care to Subjective Well-Being

The interview schedule included questions regarding the positives of care (responding to the identified gap in knowledge – carer well-being typically theorised from the burden and deficit model). Out of 30 participants, 26 responded positively that care brought positive outcomes. Analysis reveals some rich and detailed accounts that can be understood to challenge the assumption that caring for older people is associated with negativity; as one carer described below:

> *"I remember one of my friends coming to visit here probably two years ago now, and she knew that Mum was living with dementia & she came, and I hadn't seen her for some time & she said oh what a happy household & I was – like – what did you expect? I think she expected something more formal. So we have a lot of fun, and my Mum is gentle and fun"* (MARY, 57).

Most frequently, carers reported positives deriving in 'feeling good about themselves' particularly referring to increased levels of empathy and understanding of care; *"In terms of empathy, I've always been relatively empathetic, but I now really do understand more about how people feel when they have to care for someone, and I have a lot more empathy with people who are suffering from things that need care."* (KATHLEEN, 56). Many respondents also referred to care as making a positive difference to their characters and how they see themselves*; "I think I'm perhaps a lot more sympathetic to other people's struggles now. So, I think it has perhaps made me more sympathetic to people".* (JAMES, 83). Respondents also reported care contributed to increasing self-esteem; *"Yes, I'm important to the person I'm caring for. I feel good about that and myself."* (ALAN, 41). Relatedly, the ideas of satisfaction and sense of success were frequently referred to; *"It's the success of every time she wakes up it's a good day. It's seeing her delight when I can do things for her that she can't do for herself any longer."* (ROSE, 63). This was often referred to concerning feelings of love;

> *"I think the satisfaction comes out of knowing that you've looked after, in my case, my wife & that she's looking lovely & beautiful & more loving than ever she was when we*

> *first met & I think that's the satisfaction that you can do these things for her & not feel as though it's a burden, it's an enjoyment to do it."* (JAMES, 83).

Furthermore, a sense of value 'for the simple things' was often invoked; *"So what you're actually striving for is simple things, simple pleasures like when she first went in the Home we'd put a bird table up outside her window, she always loved the birds at home & she got a lot of pleasure out of that saying – look at that bird there & you'd come away & you'd think oh that was nice."* (LORNA, 62). Some carers talked about appreciating things such as 'time on their own' before they were caring, they took for granted; *"She's happy with me, and I'm happy to go there because she's a lovely lady and when I do find time to myself I do really, really do appreciate it that much more, whereas prior I had freedom all day, and every day maybe I wouldn't appreciate it so much."* (CERYS, 63). This can be understood to relate to the previously identified theme 'self-actualisation and personal growth'. Respondents pointed to these ideas as increasing positive emotional well-being states and, in some instances, contributing to positive intra-family relationships. *"So I am pleased I can do it, we have got a very close relationship which I love. I have got her close to me, which I love, and I feel – I'm not sure proud is the right word – but quite satisfied that I have done my best & am doing my best for her, so there's something quite warm about that."* (ANNA, 50). It is worth noting, that the majority of the participants who expressed positive feelings towards care described working in paid employment either full or part-time, a sub population of carers that are identified in the empirical literature as particularly at risk of experiencing increased negative well-being outcomes. (See Chapter 5.3.3)

Furthermore, the extract below describes finding positives in unusual settings; in the case described below, during a crisis situation in the AE hospital dept*; "Sometimes I've found that like when we've been in A&E together the 3 of us, my mum, my dad & myself, it's quite nice just the 3 of us sitting there…that's all quite nice really, sort of sitting there just talking, it seems ridiculous in a way, but a little bit of quality time really, just the 3 of us chatting like it used to be."* (ALED, 46). In addition, one carer described how coming back to the family home after a parent died to look after the remaining parent helped to deal with the grief and feelings of loss; *"We sort of helped each other, the grieving process, I needed him we were so close to her [parent that had passed]."* (CERI, 47).

Finally, in contrast to the majority of participants, four out of the 30 respondents said there was nothing positive to say about care;

> *"I've read about reward in care, but I've never felt it, that's what I always liked about going to the gym because it was just me time I would spend – I wasn't going to a meeting, I wasn't going to my mother's, I wasn't at home, I was just on my own & just connecting with strangers I suppose in a very different way & that was like the real me then. Damped down is the only way I can think of explaining how I am now*." (DELYTH, 67).

Another further response was provided to the question of positives; *"No, I can't. I have been asked that before & I can't think of anything positive about this situation."* (TRYSTAN, 77). It is important to note that two of the responses who have reported no positive elements to their well-being reside in low WIMD areas (1 and 2), respectively. These participants also reported receiving no help or support in their caring roles, were co-resident with the cared for, and had their chronic health conditions.

These accounts above describing the positives of care can be broadly identified as aesthetic and virtuous in origin belonging to the Aristolean eudaimonic conception of well-being and align with the literature review findings (Chapter 2.5). They can be understood as contributing to a type of sociality that encompasses more than individual accounts of subjective well-being. In contrast, the aforementioned reductive policy applications 'well-being as happiness and the absence of pain'. It is noted and drawing upon the critique of active ageing literature presented in (Chapter 3.10) that the inherent value of caring as a meaningful practice and as part of human flourishing is presented through these findings, which stands in contrast to the reductive neoliberal active ageing paradigm. In this way, I suggest that well-being in the context of older age is not confined to the utilitarian, hedonic perspective that proffers keeping active and well, and economic productivism as idealised states that contribute to full citizenship in older age. The theme of the positive value of care has highlighted care as contributing to positive subjective well-being states, characterised as life-affirming, doing good, a sense of achievement and satisfaction or success. An additional value of care was identified in the analysis understood as contributing more broadly as sociality.

7.4.7 Sociality

"My friend, she's the cleaner, the carer and her friend." (ANGHARAD, 54). A broad consensus was identified in participant analysis that showed the inherent potential of care to be personally fulfilling and contribute to positive subjective well-being. These accounts travel beyond the hedonic 'happiness' accounts and are understood by participants as of 'broader social value' through relating the idea of doing good and satisfaction to broader terms to 'making a difference';

> *"I want to make a difference, not just for our own situation but for everyone else because I just don't think it's right; I don't think we've got it right in this country at the moment. I'm sure it's worse in other places, but someone needs help and care, and then society is just allowing them to be swept under the carpet and if they haven't got the family to pick them up and we just don't know what happens to them"* (GRUFF, 73).

Understood in this way, these responses show that carers recognise their care as something of value to themselves and, as noted, care more broadly value to society. This identified theme aligns with the idea of 'caring democracy' argued by Joan Tronto (2013) that care is good for society and good for democracy. Exploring the ideas further with respondents, some carers noted how their caring roles could provide them with opportunities for deeper reflection on the meaning and purpose of a good life;

> *"Rewarding? I mean, it does give you a chance to kind of slow down in life; otherwise, often you're just running, whereas a caring role, no matter where you are in life it makes you stop & it makes you consider things differently, it takes you out of the rat race & gives you space. It's definitely rewarding in the sense that it gives you an opportunity for you to have a different path in life or consider more carefully what you do in life. It also just gives you time to be able to spend maybe – go & see that person, that friend which you normally wouldn't have time to see, so in that sense also you can see having more time as positive, having more what you would normally call relaxing or waste time. We call it caring time, but it's a positive time to have time to just sit down with that person, like my grandma & talk to them for 2 hours about her life. Most people don't have that, so it will definitely enrich my feeling or the past & the family & more local relationships, maybe next door, I get to know the community more so it's rewarding in a sense of community & more meaningful relationships I think."* (BETHAN, 24)

Furthermore, respondents described broader social networks and friendships as of particular value and variously enhanced. Friends were often referred to as helping out in practical terms, as the following example illustrates, and several carers described how a friend or someone who is part of the carers extended social network becomes a support for the cared for;

> *"One of my friends actually helped my mum came out because she was having difficult cleaning, so we paid for my friend to go in, she would go in 2 or 3 hours a day & only doing a tiny bit of cleaning because there wasn't much to do, but she'd take my mum for a walk when I was in work & because she knew my friend she trusted her, she's known my friend for 30 years, so she enjoyed that, that was nice & again it's a different outlook, she would tell her about her kids & stuff like that, a different outlook on life, so that was nice. (JOANNA, 51)*

Another participant spoke about taking her friends to visit the cared for whilst she was out socialising; "*They might [friends] even pop in if they were with me or because of where my father lives in the town if we were going to meet up then we pop in just to check on him during the rugby or whatever."* (ANGHARAD, 54). The carer described this as essential for her well-being - that her friends understood her caring situation and supported her in the care she provided by being part of the *"Little community of people who he knows." (ANGHARAD, 54).* Participants also referred to community settings where they felt supported to be able to take the cared for, an example provided in the following referring to a local hairdresser;

> *"I take her to my hairdresser where I've been going for it's probably 30 odd years, I know them well, before I started taking mum there I did say look please be warned, mum sometimes says things that come across as quite cruel, but she doesn't mean it & it's her dementia ..she says it'll be fine you know so they obviously have taken it on board I do know that when we're in there, I can relax which ever lady is doing mum's hair they're keeping an eye on her, I can have my own done, I don't need to worry about what she says."* (FLO, 51)

Contested debates within the happiness literature were outlined in Chapter 2.8, and they broadly relate to ideas of happiness as a constitutive of well-being to hedonic or eudaimonic traditions. Theorists such as Austin (2020) argue that western conceptualisations and policy applications of happiness belong to a hedonic tradition. However, the accounts above demonstrate that many carers' happiness contains ideas that relate to more than a positive emotional state; they also connect with ideas relating to virtue and sociality. Aristotle's eudaimonic account of well-being reflects these ideas and capabilities theorist Nussbaum writes: “Happiness is something like flourishing human living, a kind of living that is active, inclusive of all that has intrinsic value, and complete, meaning lacking in nothing that would make it richer or better.” (Nussbaum, 2011, p. 171). The findings reported in this study relate to well-being as ‘eudaimonic’ in origin. The ‘eudaimonia’ approach to happiness stems from individuals' interaction within society and others and emphasises non-material pursuits such as genuine relationality and intrinsic motivation (Deci & Ryan, 2004). These findings show that carers understand their care as contributing to their broad sense of happiness and relates to virtue and the ideals of Tronto’s (2013) ‘caring democracy’.

7.5 SECTION SUMMARY

So far, the analysis has identified well-being as a subjective and relational state that encompasses ideas of responsibility for self-care, interdependence and a positive value of care. Findings show that carers attributed a personal responsibility to happiness attainment and identified the theme of ‘looking after yourself. A related aspect of understanding well-being was the connection to the cared for and their well-being. In addition, I have argued in the context of care, that responsibility for self-care experienced by the carer can result in a denial of the need for support to care. The value of responsibility for self-care is theoretically situated in this study within what is referred to (through the capabilities approach to well-being) as; ‘means’. These are the social (policy-driven) and economic resources to which individuals have access and capabilities to achieve valued functioning’s can be met (Yerkes et al.2019). In this study, I identified ‘active ageing’ policy discourse as ubiquitous relating to care for older people. Active ageing, characterised by an emphasis on economic contribution, individualism and responsibility for wellness, denies relational personhood. This obscures the negative outcomes that can be experienced due to care and the complexity of extrinsic factors such as class, gender and ethnicity (Ward, 2015, Emirbayer and Mische, 1998). Finally, I examined happiness accounts of care. I related the virtuous in origin examples of happiness to the key debates concerning happiness and well-being, connecting these ideas to sociality and caring democracy.

The following section responds to findings relating to the socio-political context of care, identified under the key themes of freedom and choice.

7.6 THEME TWO - FREEDOM CHOICE AND CAPACITY

Conversions converting means into opportunities for well-being. ***Sociopolitical context*** **Theme 2** **Freedom and choice**
Caring context
Choice
Burden
Unhappiness

The theme of freedom and choice was identified through the analysis based upon an exploration of the ‘conversion factors’ that contribute to well-being or ‘secured functioning’ and broadly relate to socio-political and cultural contexts in which the care is situated. Findings suggest that freedom and choice for carers are limited because of the caring role. Based upon critical engagement with the literature and presented in Chapter 3.4, this can be attributed to the normalisation of care as a private and individual concern. Furthermore, the literature review identified an epistemic tendency to theorise well-being primarily based on burden discourse and focused on subjective outcomes. It was suggested that the focus on subjective burden has resulted in a lack of attention to the broader contextual factors such as socio-political and extrinsic contexts.

7.6.1 Freedom

“I can’t just grab my bag and go.” (JOANNA, 51). Carers described positive well-being in association with the ideas of ‘being free’ and ‘exercising freedom’. These concepts are described in detail within the broader literature on well-being (presented in chapter 2) and are a vital feature of well-being theorised by CA theorists Sen (1999) through the idea of ‘substantial freedoms’. Explored further in the ensuing discussion, the concept of freedom can be understood in various ways in the literature and conceived of according to Sen’s CA, it as an expansive concept that entails more than an exercise of choice but the capacity to

exercise options that is constitutive of our well-being (Sen, 2001). It is useful to highlight Sen's use and extension of Fredrick Hayek's (1960) distinction between two types of freedom; 1) the derivative - the actual use of freedom, and 2) the intrinsic – the importance of freedom in making use of choice. The analysis below draws upon this distinction to reveal the intrinsic and extrinsic aspects of freedom identified by carers during the interviews.

Carers interviewed in this study (N=15) related freedom with reference to the idea of lack of freedom aligned with understandings of extrinsic freedom- equating it to not being able to take holidays and breaks; *"Having the freedom to be able to say OK I'm just going to go to Spain this weekend, OK I'm going to go to Scotland & hike up a mountain for two days kind of thing."* (CERI, 47). Many respondents associated lack of freedom with a general feeling of restriction and curtailment; *"But I always have to think ahead, I can't just grab my bag and go."* (CADI, 41). The lack of freedom was attributed to causing negative well-being experienced within both the subjective and material domains. Firstly, concerning subjective well-being, "*But when you are in an environment which is fairly locked in, that in itself has huge ramifications for your mental well-being because you are not free. You are not able to just be spontaneous, to do something that you would like to do."* (KATHLEEN, 56). 'Lack of freedom' was elaborated further in the interviews and several participants referred to the idea of escape; *"I think there's a lot of escapism within caring roles definitely because sometimes it becomes too much & there's nowhere you can go so you try to go somewhere within the space, like use your mind or just speak a little bit later because then you're just of kind in your dream world."* (ALED, 46).

The suddenness of the caring role was reflected upon by some associating it with a sense of loss or feeling of experiencing profound change; *"So I've gone very much from a 41-year-old outgoing person to being somebody who is constantly caring & working full-time."* (CADI, 41). Some carers expressed views relating to the caring role itself as well as aspects of care, some stating clearly that they would not choose overall the caring role; "*It would never have been a choice that I would have made, I would never have taken that sort of career choice if it's a career in an ideal world it's not what I would have chosen which I suppose its the same for* *many people."* (MARY, 57). Others reflected on the 'journey of care', described as; *"A terrible journey that you are sort of thrust into"* (ANGHARAD, 54). *"If somebody said to me, you know in 10 years your life is going to change, I probably wouldn't believe them."* (JOANNA, 51). And finally, one carer stated, *"To suddenly be that horrible phrase, 'just a carer" (CERI, 47)*.

In addition to freedom as something extrinsic (being able to break free), it was also described as an intrinsic 'feeling'. In the extract below, the carer understood freedom to mean simply to 'feel free' and not having to worry; *"So the well-being it's just being able to have peace of mind really that they're OK, that frees you up to able to do what you want to do and have as normal a life as you can because it can be all-consuming when you're in the middle of it all"*. (ALAN, 41).

Freedom can be understood, therefore, as having an internal subjective meaning, "having peace of mind", and external structural meaning, "being able to [physically] take a break". Applying the theoretical framework and reflecting the CA and the ethics of care perspective to the idea of freedom, we can understand that freedom and choice are dependent upon certain 'conversion factors', including socioeconomic factors. The following extract illustrates this. The exert below is from a carer who identifies 'having a holiday' as the most beneficial activity she could do that would positively impact her overall well-being. But because of financial constraints, she is unable to 'be free' and therefore enjoy ultimate well-being. Her caring context shows that she lives with her mother who has dementia and cares for her full time. The carer works part-time because of her caring responsibilities and lives within a high WIMD ward.

> *"If every time I want to go on holiday, then I pay somebody to live here like 24/7 for (cared for) then that's something like £1200 for the week ..this is the real crux, that's when I feel dissatisfied if I can't do what I want to do like that. That's the real thing, and the option is to move (cared for) into a Care Home for a week to go on holiday but I don't want to do that, so this for me is the issue really the fundamental issue, the*

> *biggest challenge I face & that for my well-being, it's all about fun, freedom, choice, flexibility, for me, it's the nub of it."* (RHIAN, 61)

This carer is working part-time and living in a relatively low score WIMD area, despite this, the carer above refers to the financial penalties and burdens that care brings and prevent her from being able to take regular holidays or breaks.

This finding shows the benefits of understanding well-being from a perspective of relational (ethics of care) and the capabilities approach. Both offer opportunities to understand the broader contextual and relational aspects of care and reflect on these complexities and is the focus of the following section below.

7.6.2 Choice and Conditions of Care

A related idea to the concept of freedom in the context of care is the idea of choice. When respondents referred to ideas of freedom, follow up exploratory questions were asked relating to their views on choice within the caring role. Responses provided were characteristically rich, with some carers referring to their stage of life pointing to an expectation that after retirement, freedom to holiday and have no restrictions is assumed, but with care responsibilities, this freedom and choice is severely curtailed;

> *"I suppose there's that that when you come to my stage in life where you think you're retiring & you've got this freedom, you haven't got that freedom anymore, that part of it is restrictive, but it's not a problem, she's my mum & I would do it for her, so it's not a problem it's just something I have to think about & to arrange & to sort out if I do go away."* (EMILY, 64).

Furthermore, many respondents pointed to the suddenness of the caring role, referring to it as something unforeseen and unplanned. In this way, freedom to care is of critical significance, and most respondents described a lack of choice from the very outset. "*Because you never plan for this, you never really know – most people don't know about this part of your life & what's going to happen because you just don't think it's ever going to happen to you"* (ALAN, 41). The question is explored based on these findings if the caring role is ever really a genuine choice; *"So I've taken on the responsibility for this & I didn't realise that I would still going to be doing it 11 years later, I thought it would be a three-year thing, restore my mum back to health, get all the services in place & then go back to my life but that hasn't* *happened, so you have to adapt, you have to adapt to what's there, but unfortunately it does feel a bit like a siege situation."* (CHRISTINE, 63). Some reflected on how their lives were before caring and how different their lives were now because of caring, noting huge changes;

> *"For 16 years, that was the way I lived my life & I didn't save anything, I didn't worry about my home. I just really was out all the time…I travelled, I had fun, but now the carer's role has come from nowhere. Of the three children, I was the least likely to be a carer because I was never interested in family. My own family, I love them, but I wasn't interested in having a family of my own."* (MARY, 57)

The carer's broader context is essential to note in relation to the idea of choice. The CA theory of means and conversions supports understanding broader factors and contextual influences that can impact the carers capacity to make choices that could support or impede well-being. Analysis of carer context showed that in particular, the carers who are an only children referred to a definite lack of choice to care, and emphasis was placed on this as a critical feature that can inhibit positive well-being;

> *"No, I literally don't have a choice; I'm the only child. There's nobody else in our family. If I left my mum to it, God knows what would have happened. I'd say that's probably one of my biggest strains really that it's just me & it always has been because, it's like children of alcoholics you grow up knowing that it's up to you to support them, there isn't anybody else, so you kind of get used to it but it doesn't mean it isn't a massive personal strain…."* (CERI, 47)

In addition, the health condition of the cared-for was identified as an essential variable. In this analysis, the carers of people with dementia or complex mental health conditions reported poor accounts and large limitations in choice. The carer here describes caring for his mother with complex mental health problems including dementia;

> *"As a son, should I allow my mum to live in squalor? Should I allow my mum to live with a fridge full of rotten food with mice droppings all over the tables & you know filthy? I think the answer is probably no, so I don't think I have a choice in that because no one else is around."* (ALAN, 41)

The analysis relating to choice also highlighted the idea of stated preferences regarding choosing the conditions on which to care and specific aspects of care tasks; *"Yes and I want* *to do it. I want to take care of [cared for], but what I don't what to do, I don't want to do all the cleaning & washing & all those sort of things that go with it."* (EMILY, 64). Some carers spoke about 'choosing' aspects of care over others, highlighting a degree of autonomy and capacity for decision making and choice in the caring role. This extract below is provided by a carer who described her financial situation as 'being well off' where they could choose to 'buy in' the type of care required.

> *"I mean, I don't like doing personal care, and she was living with me, and she wanted me to do the personal care, but I was like, I was working, and I just find that I don't like doing it, I find it's too intimate, you know with somebody who's a family member – but eventually she got the care, she loved the care package, she thought it was amazing, and she loved the people coming in and looking after her and washing her hair & talking to her. I don't know why she had fought so hard."* (HANNAH, 61).

Some carers pointed to a lack of support that curtailed their choice, freedom and feelings of well-being; *"The most stressful and difficult thing in caring? Just the loss of autonomy and support not being able to do what you want when you want it that's probably the most difficult thing."* (DELYTH, 67). Similar accounts were provided by (N=5) carers who expressed that they would like respite and activities for the cared for but that it was simply not available or suitable for their needs; *"It's my lack of freedom as well. I don't have that. I don't have the freedom to say right that's it I'm off for the day. She won't go to bingo or anything like that."* (CADI, 41).

Frustration and anger were expressed by several carers who referred to the refusal of the cared-for to receive any external support or help with their care; *"No, he wouldn't have anyone coming in, and that would be really helpful for me."* (MARY, 571). These findings corroborate recent research literature (Rand et al., 2019). Investigating this further with some participants revealed oppressive relationships with the cared for and the devastating effects on the carer well-being, illustrated in the extract below.

Several carers referred to needing and wanting care support, but the cared for resisted external 'replacement care'. *"She refused it & she refused to have anyone in or even go to a*

Day Centre, she just wouldn't accept it & nobody can force them you know". (ALED, 46). This is important as it demonstrates the consequences of devising support around the carer dyad relationship. The cared-for voice is dominant in these accounts, and the carer's well-being depends upon the cared for agreeing to forms of replacement care and support.

> *"She had carers when she fell about ten years ago, she broke her hip, and they arranged a package, but then she got better she didn't want it. She refused it & she refused to go to a Day Centre, she just wouldn't accept it, and nobody can force them you know…I had a quiet word with the doctor then afterwards, and he said well until it gets to a crisis point there's nothing you can do & that was so hard…because of her illness mentally she was so nasty. Mentally, it just – I wanted her to die, I was glad, I was waiting, honestly I can't it's just the truth I wanted to be ill myself, I wanted to become ill myself so I didn't have to put up with it any longer, I couldn't cope, it was awful."* (JOANNA, 51).

This is a significant finding as it highlights the deficiencies of a carer dyad theorisation and how the cared-for voice and choice are heard at the expense of the carer in policy and practice. This aligns with recent work where well-being policy can be understood as 'carer blind' in that services tend to support and accentuate the rights and choices of the cared for to the detriment of the carer's well-being (Teahan, Walsh, Doherty, & O'Shea, 2021). A relational account of care that attends to power relations and provides an ethical framework for judging what contributes to good care is provided by Tronto's (2013), and the extracts above demonstrate a need to respond to these complex issues regarding rights, voice and choice.

7.6.3 Expectation to Care

"My father's a burden, no he's not a burden" (ALAN, 41). The theme of burden as an outcome of the caring role is vital in the literature review. Described here, respondents pointed to feeling burdened when describing the reality of their caring lives. In addition, a seemingly contradictory response is expressed as feelings of 'gratitude' and a sense of reward. This conflict, caused for many negative subjective well-being states described as guilt and anxiety; *"It sounds awful, but my father's a burden. He's not a burden & neither was my mum. I don't want to have the intervention of carers & things. I don't know it causes me so much stress."* (ALAN, 41). This theme is elaborated in further extracts; *"I don't wish to be here, I don't want*

to be here, I don't want to be doing this, but at the same time I am so grateful that I am here, I am so happy to be doing this, so you're constantly, you know it's a balancing act." (ROSE, 63). I suggest that this seeming tension and ambivalence stems from the ideal of well-being as individual happiness. This doesn't square with the relational account of well-being that carers articulated in this study (see above theme 1). Tensions and ambivalence towards the caring role are critical findings in this study and contribute to a recognised knowledge gap (Pillemer, Suitor, Baltar, 2019). This can be explored and examined in further detail by analysing the idea of well-being.

Carers expressed conflict regarding the caring role, but with little alternative and an expectation to care. Many respondents described how despite the negative states that care can bring about and potential damage to their well-being (particularly in the form of negative impact on freedoms health and mental well-being), they had little option but to care; these were described with reference to 'duty and obligation to care'. This was expressed by a participant whose spouse had Parkinson Disease. The carer described how health professionals and systems assume that the family will provide the care, despite the severity and complexity of the condition. The participant identified as is a retired health professional and reflected on her assumed professional capacity to care for her husband she observed when interacting with medical and health staff; *"No one [referring to medical professionals] asked can you cope with this?, are you prepared to do it?, it's just assumed you're going to do it, even though it's incredibly demanding and complex work."* (ELLEN, 78). A further example of this expectation to care was expressed by a participant who described how, as a large family, the siblings developed a complex rota to provide support and care to their mother with complex needs and frailty. During the interview, this carer referred to social care systems expectation that the family would provide all the support; *"I said about what the District Nurses had said in their paperwork & it was like, 'family have got her on a rota, so the family are taking care of her', so basically the message was we [district nurse] don't need to do much we can just sort out this leg & that'll be it we'll be out."* (IVY, 61).

The ‘normalisation’ of family care and female care is recognised and theorised within the feminist and carer literature and identified and expressed within Government policy as described (as outlined in literature and policy review). However, it is argued here in line with care and feminist theorists that it is more than a psychological response to perceived expectations to care. Instead, it is bourne out of deeply entrenched normativity that places care firmly within the home. Therefore, as women’s and girls' work, it is a reinforcement of patriarchal gender norms. Thus, a theorisation of well-being within the context of care begins from recognising the gendered nature of care and how it operates within patriarchal lines.

In this way, we can understand the contradictions between recognising care as harmful to their well-being as many of the respondents do. In the same response, carers state that they feel duty-bound and expect care. Relational theorists stress that persons' self-identity and choices are embodied by the social practices (cultural, linguistic), social group identities, and historical contingencies informing individual practical identities (Mackenzie et al., 2014).

The analysis identified that the choice to care is imbued with normative assumptions expressed as ‘duty to care’. However, from a capabilities approach to well-being, it is also important to note that choice is based on resources. For example, in the response below, the carer expressed a view that if you didn’t want to care, you wouldn’t. Her caring context shows that she lives in an affluent area (WIMD score 9).

> *“I used to travel a lot with friends as well, go overseas with friends & really quite adventurous. I can’t do that anymore because who would look after [cared for] & the answer is nobody.. but there again I’m happy to do it & if I wasn’t happy to do it I would probably find a way of not doing it, do you know what I mean? No, it’s not what I would choose to do, so it’s a complex one that because I suppose if you really really don’t want to care for somebody then you don’t, I don’t know. I couldn’t cope with that. That doesn’t suit me.”* (ELLEN, 78).

For many, the sense of duty or expectation was expressed as unqualifiable, or an absolute; *“But my sense of responsibility and my sense of loyalty and duty to my mum is more important than anything else, and to a certain extent I have depressed my desires and goals for that but*

I can't do that indefinitely and can't become this robot you know on auto-pilot all the time." (ROSE, 63). Further analysis around the subtheme of expectation to care identified a gendered dimension. The interview study sample included eight male carers, a unifying feature of the male carer response to the subtheme of duty was a very strong positive statements concerning duty, and the majority did not reflect on or note any adverse effect on themselves because of this vital sense of duty to care; "*What I do I take for granted that it's my responsibility to do it. You know I've never thought about being a carer or being called a carer, it's my duty to do it".* (JAMES, 83, 83). This analysis finds a strong sense of duty articulated as in particular amongst the male participants; *"Because at the end of the day you owe your parents everything, your whole existence comes from your parents, so you have a sort of duty of care really, it's not a sort of in a qualified position, it's all on the duty of care sort of aspect*." (EMILY, 64). Other male respondents pointed to spousal responsibility as a married couple of many years; *"When you're married you take it for granted, it's your duty to do it I feel & we've been together, we've been married 57 years*." (CARWYN, 89) This sense of duty was expressed as an end in itself and didn't require any further qualification or explanation. One contrasting view to most responses was supplied by a younger male participant who reflected on caring for his mother full time with multiple needs, including dementia. Although he refers to a strong sense of duty, he also described an accompanying sense of loss regarding the relationship that he previously had before becoming his mother's carer; *"We used to have a pretty good friendly warm relationship with my mum, we would do stuff together & now; unfortunately, I feel a lot of grief in saying this that kind of is my duty, it's not what I would choose to do now, it's what I have to do."* (ALAN, 41).

Some carers described intra-family conflict when expectations of caring clashed with family members, the extract below are from a participant who is referring to a sibling who is not involved in the care of the mother who has dementia;

> *"From your children, you expect it, my mother has always been a very caring person, she's done everything she can to help us all, and you just think it's role reversal he [sibling] did go and see her in hospital and things like that but, it's as if it's not his responsibility…because it hurts my mum and that's what annoys me because I think he should for my mum's sake, he should do it more, not for my sake, I don't care about it*

> *making it any easier for me, but for my mother's sake because he's her son and he should do it for her."* (JOANNA, 51).

A further example of intra-family conflict was expressed by a carer who described how her husband would often complain about the amount of care and time she had to give to her mother; "*He has said to me, you know you have to be careful about how much you do…its caused a row or two, it is what it is."* (KATHLEEN, 56). In addition, in this analysis, a lack of alternative 'good caring' options was also critical concerning carer freedom and choice. Therefore, the next section will discuss the 'lack of alternatives' for good care.

7.6 4 Lack of Alternatives for 'Good Care'

The idea of choosing to care triggered discussion around how carers depended upon support to mitigate the consequences of lack of choice outlined above, however as described and discussed below, experiences of support did not readily convert into positive well-being outcomes. In many instances, they can be understood to create adverse and even harmful consequences. Many carers felt they had no choice but to care, with many referring to a lack of alternatives, such as daycare provision or quality institutional care and respite. Tronto (2013) writes that within the neoliberal context, the market (in this case, the social care market) is the platform that can resolve disputes, allocate resources and permit individuals choice. Some respondents pointed to helping the cared for to remain in their own home, and the alternative of entering residential or nursing care was again (as discussed under theme of freedom) overwhelmingly considered a negative option; *"Well, I think the positive thing is that I feel I'm really helping both of them live more independently. I mean I'd never want my mother to go in a care home unless it was completely unavoidable."* (KATHLEEN, 56). The idea of maintaining the cared for independence in their own home – is considered for most participants interviewed the ultimate goal, and the carers report that their well-being is enhanced by avoiding the negatives of care home entry. *"I wouldn't feel comfortable if she was in a nursing home or anything like that only because it wouldn't be fair on her to put her in a Home. I think a lot of people would be like that."* (MARY, 57). Many of the respondents referred to buying or procuring care support packages as an experience that many of the respondents referred to and is examined in further detail below.

Out of the 30 interviews conducted, N=16 reported receiving care support packages, and respondent accounts relating to support services were overwhelmingly described in negative terms, with interviewees referring to examples of inadequate and (in several cases) poor or bad care. The experiences and circumstances described were particularly distressing to hear and affirmed the need for the data analysis to address justice informed questions regarding care sustainability.

Inconsistency and uncertainty were vital ideas relating to the standards of care, and many referred to the high turnover of domiciliary care staff; *"Yes it's really been exhausting. Some of them are professional & they are so on it & amazing & other ones are just standing there looking round the house."* (ANNA, 50). Several respondents described poor care and raised safeguarding issues*; "Sometimes things were definitely overlooked, they [domiciliary care staff] weren't great, ..they'd miss a tablet, but when my sister-in-law goes there she brings her young children, her young grandchildren, so the last thing you want is for a little child to pick up a tablet, a heart tablet, so it was things like that."* (ANGHARAD, 54). Insensitive, undignified or inadequate were consistently referred to particularly from carers caring for someone with dementia; *"On the odd occasion he has frozen Wiltshire meals, you could see they hadn't actually dished them out on to a plate, they'd given him the meal in the plastic container, well my father-in-law would never eat a meal in a plastic container, he's a traditional old man, he'd have a knife & fork & plate, so it's just things like that*." (KATHLEEN, 56). Some participants described how complaints were mounted, and alerts were made to the care agency; *"We did use to have to phone the care agency quite a lot [to complain] although there was a care plan the carers haven't got time to read it a three-sided document…"*(HANNAH, 61). Some reported improvements in care were realised, but the carers expressed anxiety that complaining may result in poorer care.

One carer described how she used to complain to the agency directly but described a strategy to talk directly with the carers themselves and understand that she can improve the care her mother receives by educating care staff; *"I've found it much more helpful to be there when the individual carers are there to talk to them & get to know them & do it in a much more pleasant way because then you understand the strains they're under as well, the fact that they're not trained in dementia care impacts badly on them as well as my mum."* (CERI, 47).

The 'lack of care' or 'bad care' was referred to as increased anxiety and stress for the carer and the wider family. Some carers described cancelling the care package support because of the increase in stress and burden it caused, and thereby placing further restrictions on their freedom and capacities to exercise choice;

> *"To tell you the truth, my mum didn't find them [carers] that good really. Some of them are better than others. Her biggest thing with him is the bowel incontinence is awful. That's the terrible, terrible thing that she has to deal with, especially as they're in a house & he's just so slow. She's got a commode downstairs, but again he's stubborn & he won't use it. And them sometimes as well they [carer] would put down that he'd washed himself, but he hadn't washed himself properly. So they seemed to want to do what appeared to be as little as possible. My mum says she'd rather just manage. In fact it got to the stage when my dad was making her get him up for 7 in the morning because he didn't want them coming in & washing him. So it was all getting a bit stressful, basically.* (CHRISTINE, 63).

Out of the N=16 participants that received support in the home, just one participant described a timely and efficient package of support put in place. This respondent reflected on this positive experience attributing it to the professional role that the participant held previously and was given 'red carpet treatment.

> *"Once the diagnosis had happened, a pretty efficient process of care packages was offered quickly. I was pretty impressed. It was quite funny because I went with my mum to the memory clinic in [Wales] & while I was there it was quite funny because the doctor there just asked what I did & at the time I was still working for the [Welsh public services] & when I told him… I wasn't trying to pull that, but I did feel like quick red carpet treatment."* (ALAN, 41).

7.7 SECTION SUMMARY

The importance of freedom to carer well-being can be identified concerning the codes and extracts where carers describe that they are not free in a derivative sense - they do not feel they can use their freedom in a way in which they see reason value. An apparent contradiction is identified concerning how freedom and well-being operate on multiple levels for the carer. The analytical framework can support understanding these tensions, providing a focus on the antecedent factors such as the condition of the cared for, the carer context (SES) and broader socio/cultural norms and ideas about who is responsible for the care and what options (perceived and actual) there are for support to care. Carers describe how despite freedoms curtailed because of care, but that they *"Wouldn't have it any other way"* (BETHAN, 24). The analysis demonstrated that institutional care was understood negatively, and alongside this, the study identified a type of internalised normativity of 'expectation to care'. Understanding freedom and applying the idea of relational autonomy to the concept of freedom suggests that the capacity for freedom and exercising of real choice is curtailed because of the lack of recognition of family care. It can be understood as unrecognised and devalued. Furthermore, a lack of alternative options for 'good care' points to structural market based and systemic failures that go beyond the agency of the carer and are dependent upon government and a collective political will and responsibility to nurture good care.

7.8 THEME THREE - DEPENDENCY AND VULNERABILITY

Observed functioning (well-being outcomes)
Vulnerability – intrafamily conflict
Isolation invisibility
Income vulnerability
Service dependency

The final themes, vulnerability, and dependency were identified by exploring the carer self-reported outcomes of care. Accordingly, it can be understood as situated within the analytical framework (see fig) focused on ‘secure functioning's care outcomes. The analysis finds that carers mainly in this sample experienced or are vulnerable to social isolation due to the cared-for condition and the caring role. In addition, the Covid-19 pandemic frames this specific theme of dependency. The interviews were conducted in Wales during the first coronavirus lockdown in the spring and summer of 2020.

Carers recognise a need for support to care. I argue that this need for support results in a dependency that carers can experience as negatively damaging to their well-being. Vulnerability and dependency were identified as theoretical lens on which to identify and understand these well-being outcomes. Nussbaum argues that humans are inherently vulnerable and have connected this idea of vulnerability to sociality. As embodied social beings, we are both vulnerable to the actions of others and dependent on the care and support of other people—to varying degrees at various points in our lives, “The body is constitutively social and interdependent,” (Butler, 2004) and it is this embodied vulnerability to others that makes human life precarious. Vulnerability and dependency are thus intertwined. (Mackenzie et al., 2014, p. 4)

This dependency is a socio-political condition caused by misalignment or poor service support. The following section is structured in two ways; firstly, a focus on relational intrafamily aspects is presented, followed by structural elements of dependency and vulnerability relating to service provision.

7.8.1 Vulnerability - Isolation

"Just left alone to deal with it". (ROSE, 63). The idea of sociality as discussed in Chapter 2.10 and findings relating to sociality is a crucial idea within ethics of care. The capabilities approach well-being and are rooted in Nichomachean Ethics. For example, the good life provided by Aristotle 'Eudaimonia' is predicated upon a social and political life setting and through exercising humans natural sociality (Austin, 2020). Therefore, the social networks, relationships and connection to family, social political and cultural institutions are of crucial significance to well-being theory and are vital they play a mediating or instrumental role in achieving other aspects of well-being, for example, subjective states. (Austin 2018). In the case of care, it is identified as a possible site for negative well-being outcomes (Stoller, Miklowski, Szinovacz, & Davey, 2008). Participants were invited to talk broadly about their connections to others and the outside world within the context of their caring role. The majority responded by describing isolation described in various forms. Mainly, respondents described physical restrictions on social connections as explained by this participant.

> "I used to belong to a walking group. Well, there's no way that I could get out now with Mum. I've had to finish that, but I have friends that I contact & then they'll say how about meeting up for coffee this afternoon because they know I look after mum & I have really good friends & they keep in touch with me & whenever I've got the afternoon free or whatever I'll arrange to meet them. I count that very important, actually." (LORNA, 62).

Some referred to their isolation as embedded with cared for condition and the need to provide social support to the cared for; this resulted in for this carer a lack of time to pursue social activities beyond the caring role, particularly in this case because of a feeling of being 'drained;'

> "I still have to be [adult child], I'm still her primary carer, but I am also her very social glue, I am her only connectedness so if I don't go round & sit & watch a film or some TV with her or I have some food with her, no-one else will & I think all 3 of those, I can probably pull off 2 & I think all 3 are too much, a drain for me to combine to be comfortable" (ALAN, 41).

Several respondents described the impact of care on friendships attributing the loss of friendships to a lack of time to connect; *"You don't have the time…we've been friends for over ten years & he's retired now, but then we started planning all these things & I had to say to him, I don't have the time for that, you know I want to stay friends with you but I don't have enough leave to keep taking days off*." (JOANNA, 51). Furthermore, many carers described 'feeling' abandoned and left alone with no possibility of respite or breaks from care; *"If I ever take a break & I can't, but I haven't had a day off since January 27th & before that was nine months previous, so there's no respite really. Things all add up, so the mental health aspects are partly a sense of being isolated, left alone to deal with it."* (CARMEN, 38). Several carers expressed isolation in not sharing or 'offloading' the everyday realities and experiences of care with family, particularly from their children. The extract below the carer refers to 'protecting or shielding' her children them their troubles; *"I tend to think well this is her time to go off & do her thing & establish her networks & her friends that will be with her all the way through her life. I don't really want to be dumping my stuff about [cared for] onto her*." (JOANNA, 51).

The positive potential of caring to counter isolation was identified in the analysis amongst a minority of participants (N=7) who referred to belonging to local community carer support groups and the importance of these groups to their well-being; "*It's [support group] almost like having new friends even though there are just 10 in the group they are talking very freely, you can tell when someone's holding something back, who doesn't want to say it or they're concentrating hard on how to re-word it, make it not sound as back as it really is, you can just tell.*" (ALAN, 41)

"Also I've not got any experience of looking after anyone before going through it, so it's helpful for me to see other people at the carers centre, go on the Zoom calls & see other people that have got different situations, to kind of learn from them in case that happens to me in any way." (BETHAN, 24). Again the caring context here is highlighted, with this carer describing a "steep learning curve" coming from higher education into full time caring for a grandparent.

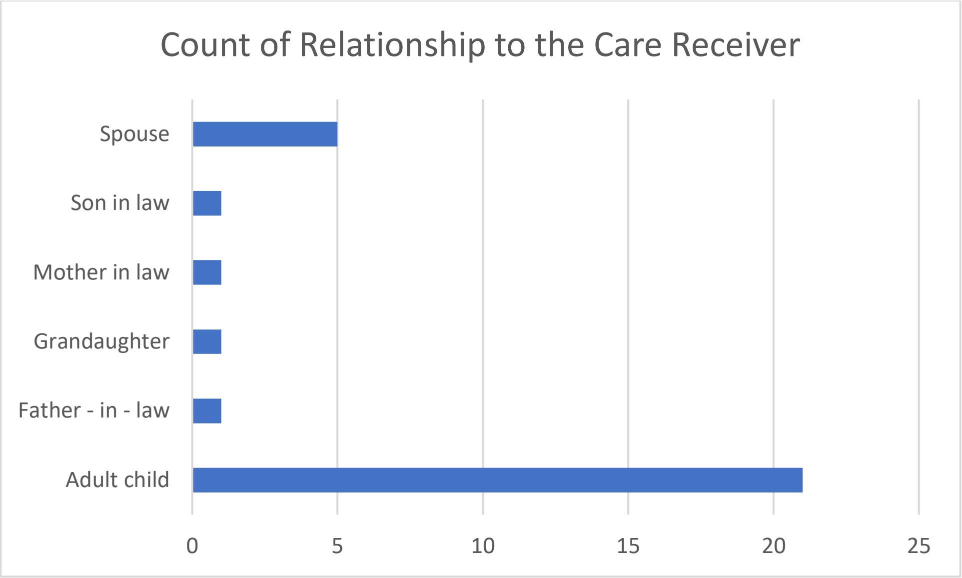
Speaking to friends was cited as especially important, referred to helping the carer feel that that care is ‘normalised’;

> *“I actually do find that is a good way to kind of make myself feel a bit better because it makes me realise & give it perspective, you know. I also find it helpful to keep telling my own self and as harsh as it sounds, I keep saying to myself this is not forever, it is going to end & I am aware that a lot of people say, oh you know you don’t want to wish her life away, but it helps me to cope with knowing that there is an end at some point soon”.* (RHIAN, 61).

Finally, one carer attributed to caring for her mother as countering her isolation and loneliness; *“Yes if it weren’t for her here I’d have quite a lonely life [working] all day by myself & we have a laugh we have a great sense of humour & we have a very very good bond so we get on well like that & that’s the highlight of the day when we chat.”* (CADI, 41).

7.8.2 Vulnerability - Intrafamily Conflict

A dominant finding in this analysis is detailed concerning the theme of ‘intrafamily conflict’. It can be understood as influencing the extent and form of carer vulnerability to isolation and was referred to as a critical source of anxiety and stress experienced by participants. In addition, the analysis showed although restrictions and depletion of social activities frequently appeared in the findings, it was not ascribed in great depth to feelings or descriptions of negative well-being states. This is a surprising finding as previous literature describes the loss of social connections as a critical variable of negative well-being (Lavela & Ather, 2010).



As illustrated in the table above, most respondents were providing care to parents (n=21). Many carers referred to intense family conflicts, particularly between siblings, where imbalances were described in terms of care responsibilities causing arguments and, in many cases, severely affecting relationships. Several carers described severed sibling relationships because of this; *"It has definitely impacted on my relationship with my brother because basically he doesn't do anything, he only lives a few miles away. I don't have really a relationship with my brother anymore because I feel quite angry that he's not supported, my mother."* (KATHLEEN, 56). A further extract below outlines how these tensions have a profound and lasting impact on family relations, here the carer no longer cares for her mother as she died four months previously, but the relationship with her siblings, she states, has not recovered; *"I hated them really for not helping out more. I felt really resentful. I did; I just felt so resentful. They all live in the proximity of where she was living, but actually, I do feel resentful. I still do."* (HANNAH, 61). An additional aspect frequently described concerning family conflict was a general lack of sensitivity felt by the primary carer to their needs and the realities of their commitments; *"A time when I had to come from work because something happened. I phoned my sister to see if she'd come up & she wouldn't; she said no, I'm washing my hair."* (MARY, 57). Further analysis identified frequent accounts of carers describing family members lack understanding, recognition and insensitivity; *"There's been a certain amount of undermining of the role and sometimes when they visit, I'd go out so they could have time* *alone & come back & all the dirty dishes would be in the sink waiting for me to come back to do it."* (ROSE, 63).

A lack of or willingness to support the carer by the family was commonly described – in this extract, the carer describes not being able to ask for help from her siblings because she feels 'beholden' to them and instead would rather pay a care agency;

> *"I say to my sisters can you look after Mum like a fortnight Friday or something & they say, oh, I'll check my diary. And I'm like all right OK so rather than it's always so much to be beholden of other people. I made a decision about a year and a half ago that really I would just go to carers [agency] rather than my family because it's just a yes or no answer then, it's pretty straightforward. Can you send a carer rather than oh let me check my diary, can I come back to you, that & that & that".* (MARY, 57).

Several carers described a negative impact on relationships with their spouse caused by the responsibilities of caring; *"I think certainly my husband he does have a problem I think that it is a problem because sometimes they think you're doing too much & you should pull back & not do as much, but you have to do what you think is right."* (KATHLEEN, 56). Another extract describes how the carer who lives in with the cared-for several times a week worries about her spouse who she leaves on his own whilst caring*; "This afternoon I'll be leaving home now in another hour or so, going over there till Sunday afternoon & leaving my husband for two days then and that kind of impacts on your own family dynamic as well, so you're trying to manage everything is extremely difficult"* (ANNA, 50).

These respondents referred to the 'intrafamily conflict' as creating stress. It can be understood as a critical factor in carer vulnerability to harm. This clarifies that the expectation of caring can put family relations under considerable strain and raises moral and justice informed questions surrounding the normativity of 'family care as good care'. As described in the care theory literature (chapter 3.4), family care can be understood as counterproductive and can weaken family bonds (Cash et al., 2013). Intrafamily conflict demonstrates how normalising family as the preferred means of support can create conditions of vulnerability to harm the carers kinship ties and broader social networks. In the following section, I outline the theme of vulnerability concerning structural factors such as income and employment and within the context of the pandemic.

At the beginning of the pandemic, with little or no guidance initially, carers reported relying on voluntary sector providers for information and support. Here we see an emphasis on individual rational choice making during the pandemic ignores the complexity and inherent moral nature of every day care highlighted by an ethics of care perspective. Furthermore, several respondents pointed to intensified family conflicts and heightened sense of anxiety caused by the lockdown experience.

> "One of my brothers at the moment is really struggling…he's quite frantic with his wife – his wife went out for lunch recently with her daughter as is allowed, & he went berserk on her when she came in telling her that she was trying to kill his mother." (IVY, 61).

Well-being as identified in the literature and policy application is typified by individualism, the personal accounts presented her can be seen to show how the individualism of care obscures the relational ontology that care ethicists argue is at the centre of defining care and our ambition for 'good care'. The conceptualisation of wellbeing (informed by the capabilities approach and care ethics) recognises and gives room for relationality and avoids viewing individuals as unconnected. This in turn, can focus the need to care and connect through care, and how when this is threatened and under the Covid-19 restrictions the subsequent harms that can result.

7.8.3 Vulnerability - Income

Amongst the participant sample, the average WIMD status was 6.7. This represents a relatively low level of relative area deprivation amongst participants. However, as detailed in the method chapter 6, the WIMD score within the analysis was 'light touch. No causal relationships were made between the WIMD of the participant's living area and the participant's self-reported well-being outcomes relating to material resources. This is because the WIMD is a location-based score, and it is essential to note that well off individuals could reside in WIMD ranked high levels of deprivation and vice versa. A discussion on the participant's responses to income and material resources questions follows. The results show in line with the literature that care increases the likelihood of income vulnerability experienced by carers. (Keating et al., 2014).

'Yes, it's a big worry, the bills.' (CARMEN, 38). Questions were asked if and how caring impacted the respondent's financial situation. The analysis aligns with recent literature findings that care has predominately negative impact on the financial condition of the carer, and that caring episode places the carer at a financially vulnerable position; *"I mean we were both earning really good money & then we went down to no money & that time we owned a four bedroomed house in [high WIMD area], now we're in a two bedroomed [in lower WIMD score area], as I say we've adapted, ex-council flat, housing association, yes it changed our financial lifestyle completely."* (LENA, 66). A significant feature of the negative outcome or loss or lack of material resources such as income was the consequences on subjective well-being described as worry and anxiety;

> *"I would say that income has a big effect on my mental health. I am worrying all the time. I know how much I've got coming, but I'm worrying about how much the bills are going to be next time & where I'm getting the money from for or whether I'm going to have enough for them. I would say that's number one pretty much on my list. I am worrying about it all the time, thinking about it, but then I can only do it when I've got money coming in. If I haven't got it, then I still worry about it, but I can't do anything about it. Yes, it's a big worry, the bills."* (ALAN, 41)

Although participants were not asked directly for information regarding their household income, many respondents referred to a reliance on state benefits (n=17) and related their caring responsibilities to a lack of ability to achieve an adequate level of income. Findings align with contemporary evidence of the negative impact care brings and identified in Chapter 2.44.1 section of the empirical impacts (Bennett, Zhang, & Yeandle, 2020).

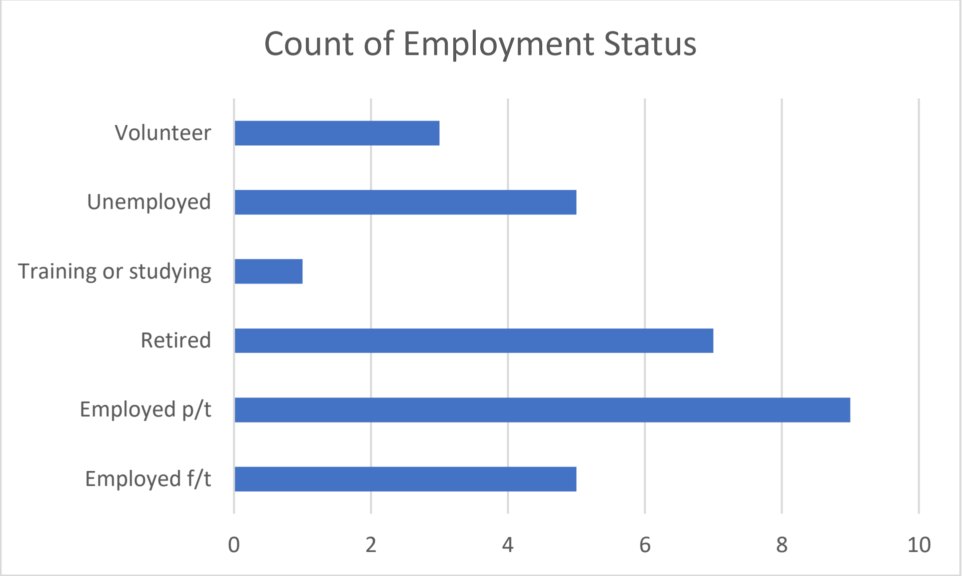
> *"I don't have income except benefits – basic benefits, kind of carers allowance & that, so I do feel it's a problem in a way, my bank account's maintaining itself at the same level, but it's just frustrating because I'd like to earn because I know that my [cared for] won't be here forever & I need some kind of plan for whatever happens in an emergency, just for myself really."* (BETHAN, 24)

Some referred to both the carer and the cared-for relying exclusively on state benefits and the experience of this;

> *"Yes because this week now we get our money every other week & this is the one week where we're going to struggle because we don't have anything coming in so if my mum needs anything I can't go & get it for her because there is no physical way that I have the financial aspect to do that so I'm going to have to get someone else to do it for me & then I'll pay them back so of course, I don't tell my mum about that because she's going to be oh well take whatever & she's in the same situation as me where she's living on benefits & this week she's got nothing coming in so it's a spiral, a massive massive spiral."* (CARMEN, 38).

Carer described care as a barrier to employment and income, often referring to limited opportunities to find and secure paid work resulting in descriptions of stress and frustration; *"I would like to take a part-time job, but then that could have a detrimental effect on my money coming in. I wouldn't even know exactly where I am financially, so I would say I wouldn't be able to do even part-time work with various commitments. You never know when something's going to crop up. You can't leave jobs just like that*. (NOA, 58).

Some carers referred to a 'benefits cycle' relating their reliance on benefits to potential earnings in the paid labour market; *"You do see jobs that are good, but I couldn't do a full-time job because of my caring responsibilities and health, but then I would like to do a part-time job but then that would have a bad effect on any money, benefits, that I've got coming in."* (ALAN, 41).



Concerning employment, fourteen study participants were employed, of them, nine were part-time, and five were in full-time employment. They described a mixed experience of care and working. Some referred to maintaining work and care as 'exhausting and demanding';

> *"What I found really difficult was to fit visiting in because being in a care home they have quite strict times when they ask you not to I'd leave work at half past 3 & I'd literally run from [work] because she's up on [residential home], to get up there to get there for 4 o'clock so we could have half an hour, 45 minutes I found that quite difficult… only gave me Saturday morning to do the other things I needed to do so in the end my husband said to me why do you bother, why don't you just go once in the week."* (JOANNA, 51)

Several carers also described how they had adapted their career plans to the care situation, in doing so, noted decreased opportunities and earning potential;

> *"Yes, of course, the caring role basically turns everything upside down in that way. You can't get a normal job because you don't have the hours free…so I do feel like it's possible to get a job, but you have to put in double the effort kind of thing, you have to kind of settle for the first thing that adapts to your timetable caring for that person rather than the thing that might be the best for your career."* (BETHAN, 24)

Many spoke about the need for flexible work practices to be able to care; *"I am lucky that I can work from home, which gives me the flexibility to look after my mother, but on the* *downside of that, how do you carve out a place out of peace but for me I'd rather work from home."* (RHIAN, 61)

> *"Like I said to you about my manager was absolutely amazing Maria, he was fantastic & continues to be. That is huge because that takes another pressure off you & to be truthful, if he hadn't have been, I might have actually told him where to put his job because your focus is I need to be here for my mum. Luckily that wasn't to be & anyway, that would be a lot to do with whether financially could I afford to do that; it all plays in. Anyway, in the end, because it was 24 hours & work was amazing but if they hadn't been who knows where I could be?"* (CERYS, 63).

Referring to a previous employer, a male participant spoke of a lack of recognition of his caring role;

> *"Oh my God, when you say this [I am a carer], they just look at you as if like why are you telling me, you've got caring responsibility. You could see that that just doesn't compute & I think possibly again being a man & explaining to other people that you do this, you can see people going why are you doing that, I don't understand why & for some people that breaking the stereotype of, well you've got a job, you've signed up to do this job, you shouldn't be having to do this, or we don't really have capacity for that was quite an eye-opener, to be honest."* (ALED, 46)

This carer described leaving full-time work because lack of the described lack of recognition and support; *"I was struggling with my job before I left it with my caring responsibilities & I think that definitely led me to think 'up yours', I mean there's other things as well."* (ALED, 46). Relatedly, several carers referred to plans to leave paid employment prematurely, citing care and work as untenable; *"I am planning to retire early though because I don't think, the older I get, the harder it is & I think I'm going to have to make a hard decision maybe in a couple of years that I'll just have to have a lower pension, but I can't keep working full-time & managing this. At the moment, I am."* (FLO, 51)

Some spoke about wanting to reduce hours, but they were unable to because of financial restrictions. This left many describing feeling 'burn out' by juggling the care and work;

> *"I mean, I can't afford to go part-time, but I think looking back with hindsight, I think it would have been helpful, particularly when my sister was having major operations,*

> *one of the reasons my well-being was low I was using the majority of my annual leave & flexi-time to support them, so I wasn't actually having a rest ever. I mean I remember driving back from [Hospital] & I could barely stay awake I was so tired & I could have done with having unpaid leave which they'd have given me, but I couldn't afford you see because I had two children at university, I'm a single parent."* (FLO, 51)

Some referred to the idea of balance and being at a tipping point; *"It's all kind of working, but it wouldn't take much to tip me over & I might have to make a decision to give up work because I don't think I can, I believe I don't think I can do much more than I'm doing now. If I was required to do more now, I think I would find it very difficult to do two things, work & caring."* (CHRISTINE, 63).

One carer described their work in favourable terms, referring to it as an opportunity for 'balance'; "I *think not having a job was really really bad for me because I need my brain to be active. Once I'd finished the Masters my brain sort of went woooooo, so I started this job in August & I've found it actually incredibly helpful because it's speeded me up a bit & I'm good at my job & it's nice to get that feedback at being competent at something."* (ANNA, 50). The findings related to employment corroborate with the scholarly literature (Brimblecombe et al., 2018) and that the paid labour market is not a level playing field (Cockburn, 2018). Carers are vulnerable to discrimination and unequal outcomes relating to income and employment.

In sum, the findings reported above confirm carers experience negative well-being outcomes, and it is suggested that this can be understood through the concept of vulnerability. Rather than articulating the negative outcome as burden (noted as the predominant narrative), adverse consequences in this analysis are understood as resulting in states of vulnerability. Through the idea of vulnerability, an exploration of the relational and material aspects of negative carer outcomes can be theorised. I identified vulnerability to negative impacts upon family and social relations and income and employment harms. In the following sub-theme, 'dependency upon services,' the idea of vulnerability is extended to understand how the state of the vulnerability results in service dependency. Based on the accounts provided, this dependent state causes negative well-being outcomes.

7.8.4 Dependency on Services

Previous discussions (see Chapter 5.5.2) identified dependency upon services as crucial to carers broad accounts of positive well-being states. However, as noted in the literature review, relatively little research aims to connect ideas of carer well-being with service provision for carers of older people. Where the evidence does exist, it points to inadequacies and misalignment of provision resulting in carer stress. The Data findings based upon this study indicate that carers experience negative well-being due in part to 1) service negotiation, 2) lack of or inappropriate service provision, or 3) poor or bad care. As such, I suggest that findings show that carers are at increased risk of vulnerability to harm stemming from their dependency on support.

"It's a minefield" (ALED, 46). Broadly, support to care was of critical significance to carers accounts of individual well-being, with the majority of respondents reflecting without which they couldn't cope; *"It's a big job to be given without some more support*."(CERI, 47). *"You can't do it on your own that's the feeling. I think there needs to be other – I mean if you're lucky – friends and family around to be part of that oh I don't know what to describe it, sort of system you know in order for the carer to keep well."* (CHRISTINE, 63).

The majority of participants in this study, reported receiving care support in some form and responding to the gap in knowledge and the study research question; the interview invited participants to comment on their experience of support and connections to their well-being. Overwhelmingly respondents reported negative experiences resulting in stress, anxiety and exhaustion; "*I had to take my mother for a flu injection down to the surgery, down to my mother's surgery, well it was just like being herded in & herded out, she couldn't even sit down on the seat, it was just like on a conveyor belt-like cattle going through you know."* (CHRISTINE, 63).

Obtaining social care services was referred to consistently, with most respondents referring to the system failing them and the family; *"You asked about carers assessment. A lot of Social Workers think of it as a bit of lip service & because they feel they are obliged to offer it, some* *of them don't see any point in it & then if they do it, they won't try to find a solution to meet that carer's needs... I don't want them saying, oh, how do you feel, what other things do you need help with & then go away & not do anything. I want someone to make things better, I suppose."* (MARY, 57).

"Whatever the social care & well-being Act of 2014 was supposed to do, guess what? It's 2020, we're still waiting. In many respects, that's the frustration that carers I think overwhelmingly feel." (ROSE, 63)

Several carers referred to anxiety and worry about care package being taken away, demonstrating the consequence of dependency on services;

> *"I had something yesterday about they are going to reassess, which is fine. When you do that, you feel a little bit nervous because the package I've got now is nice; it allows me to do the things I want within reason, but I always think are they going to take it away rather than other carers say they might give you more. They might, but they might give me less as well. I would fight that anyway, I'm sure, but I've got it all back & then to reassess, but to go in the winter are they going to have the staff? If the care homes need to up their staff & are they going to get the people?"* (LORNA, 62)

Consistent with empirical evidence identified in Chapter 5.3.6, carers of family members living with dementia expressed feeling overwhelmed concerning a diagnosis of dementia and left alone to seek help and navigate the systems; *"It would have been so nice to have somebody to hold my hand through it a little bit more – not a doctor, I'm not a dementia expert."* (EMILY, 64). Another respondent described feeling unsupported and incredulous at the lack of support offered; *"It is the only terminal diagnosis given where there is absolutely no follow-up, they just said; 'here's a leaflet."* (KATHLEEN, 56).

Arranging support was consistently described as negative and stressful. In the extract below, the carer describes arranging social care support for her mother after a crisis (fall) and refers to her sister, a practising social worker. Despite this professional knowledge and experience, the carer still described stress concerning service support;

> *"But Social Services there were like barriers at every turn. It was like as if my sister was ringing from a vacuum somewhere that was very stressful for her as well, my sister as well & I mean she knows how to navigate the system...it was an absolute nightmare in that way & that makes you so frustrated that all you want to do is rant & rave &*

> *shout at everybody in sight especially when it doesn't do any good for your blood pressure like & your well-being I suppose."* (MARY, 57)

Another respondent noted;

> *"The system doesn't help families; it doesn't help the families to cope with what it is that we're trying to do. We're trying to give her that positivity, but it's actually straining us as well & I think with covid & this whole thing about separating from everyone to keep the people that you're with safe, it definitely impacts on your own mental health & well-being for yourself"* (ANNA, 50).

Carers referred to levels and number of hours often provided as minimal and inadequate and unable to meet demand, and many carers expressed concern and alarm about this. Several referred to a simple lack of support, referring to needing to be in 'real crisis' to get the help they needed;

> *"I don't think I have a choice, but as we know a lot of people have an unrealistic view of what Social Service & care is, it doesn't just magically fly in & the limits at which she might get put into a Home are quite high so the fact that she lives in a flat which she doesn't clean & becomes infested with mice & she doesn't wear clean clothes, or she's doing things which aren't rational you know, no-one's going to go & fix, Social Services don't fix that, so I'm there running around trying to keep things what I would class as a decent nice way to live, but then you go like shit I've got an assessment coming in should I have left it really crap because actually am I covering up how bad the situation is*." (ALAN, 41)

A further related finding was identified and articulated as 'frustration' not only because of service navigation but also referred to as a lack of direction from services, particularly around times of crisis, as one carer described;

> "*I wanted them [support service] to make the decisions we needed them to make this call. I'd be kind of comfortable with that where I feel it's always the responsibility of us [carer] seems to skirt around the edges & I think sometimes greater clarity would make life easier & the fact there is completely inconsistent depending on which agency you're dealing with, you get a completely different allowance on most of what you're allowed to do."* (LORNA, 62). Relatedly, services were repeatedly referred to as 'red tape' as one carer described, the bureaucracy surrounding care support was understood as contradictory;
>
> *"In one way, they [state support services] want it informal & in another way, they want it formal. So your informal as much as they don't pay you this & that but then it's formal when you come to apply to the social worker then there's formal when you have to get your carers, your personal assistant, they have to be vetted by the social service etc….It seems in some ways they are involved & in other ways, they are not, so we have got a certain amount of input. Am I making sense?"* (RHIAN, 61).

In many ways, the experience of obtaining care support can be understood as revolving around the system rather than the carer. The carers describe a contradictory system of support where services are defined as absolved of responsibility for decision making concerning the cared for but involve the carer in a high level of bureaucracy and ‘red tape’ that is necessary to obtain support. This is a crucial finding of the analysis and aligns with recent work by Keating et al. (2021), who describes how the well-being of carers is often muted by the prioritisation of what the authors describe as financial aspects of the well-being of the system (Keating et al., 2021). Further analysis showed that care services were causing stress and anxiety; they were also not aligned to what carers identified as supportive. This is illustrated in the following extract below, where the carer recognises the support received allows her to continue with paid work, but as she continues to talk, she becomes upset because what she identifies as having the most significant positive impact on her well-being is respite, as she describes as ‘a private life’;

> *“It’s minimal; it’s not minimal. I get about 30 hours per week which sounds a lot, but it’s not really when she needs 24/7 care. I would like more in an ideal world. I would like somebody to help on the weekends because Saturday afternoon and Sunday it’s only half early morning calls and then sometimes in the evening I would like evenings so that we could come upstairs and sit and watch TV. So it’s adequate. The focus, I think, is to allow me to work and to continue with my day job, but nobody then really starts to consider – you get low with this – what about my private life? I would like somebody to sit with her in the evenings so that we can sit and watch TV on our own. It seems trivial; why do you need that? You’re in the house anyway, but that’s what I’d like. So I think I’m grateful for the help I do get so that I can work. It’s work that I enjoy. It’s not just working – it’s work of my choosing and studying of my choosing, but there’s no flexibility around fun really which really for me that’s almost as important, that’s being able to work.”* (MARY, 57).

This final extract offers insights into how support services for carers can be understood as designed around the idea of productivity belonging to broader values within neoliberalism that confine ‘productive’ as a contribution to the paid labour market, and discussed in detail under active ageing Chapter 3.1. Although, as a family carer, we can see that the care provided to older people lacks recognition as a ‘productive’ contribution, it follows that any support that is offered to carers is support to participate in the paid labour market. Therefore, this support can be understood as narrow and deficit and, in many ways, can perpetuate and damage carer well-being, leaving them exhausted and strained and vulnerable to negative well-being outcomes across all domains.

Discussions with participants focused on the context of the pandemic and questions were asked regarding material wellbeing and specifically in relation to support services such as care packages and day centres. Participants referred to these services as 'a lifeline' but in the context of the pandemic, they were reported as either closed or limited. In most cases the shrinking or withdrawal of support resulted in an intensification of care tasks and negative wellbeing outcomes. The majority of respondents in this study reported cancelling care packages and reflected on the impact of withdrawal of support specifically relating to negative subjective wellbeing states; "*I think it makes me, I think I'm on edge, I am never sort of relaxed, there is always a kind of frustration I suppose and not being able to cope, that's what I feel, and overwhelmed."* (CERYS, 63). Reflecting on the cancellation of the care package and the impact on her wellbeing one carer described how this negatively impacted on her own wellbeing *"So I cut all the carers out because I thought that was a risk I could minimise so therefore I did it all myself & then I did suffer for that and I won't be doing it again going forward no not whatsoever"* (MARY, 57). Not only did carers report cancelling social care packages because of the perceived risk of contracting the virus, but several reported cancelled community medical visits, thereby leaving the carer and the cared for at significant risk:

> *"I do feel isolated sometimes because when I was putting the support stockings on, it was ripping off the scabs & then the scabs would bleed & then the infection would come & no nurses would come out to visit, due to the pandemic, I find that's a huge responsibility on somebody who cares for somebody, because I'm not a nurse. With this pandemic I've kept very isolated yes then because I have no support from professionals."* (DELYTH,67)

These excerpts reinforce recent empirical reports (Bennett et al., 2020; Giebel et al., 2020) that carers were left to 'go it alone', resulting in considerable stress and anxiety, factors consistently shown to contribute to negative wellbeing states. Furthermore, a critical ethical perspective of the impact on carers in the context of the pandemic brings to the fore important questions regarding the responsibility of governments to vulnerable groups such as carers, and puts in question the extent to which carers can reasonably be expected to ‘go it alone’, given the well-established body of evidence that documents negative wellbeing outcomes?

The central role of equality in an ethics of care perspective is useful to highlight here, as Sevenhujjsen, (1998) writes; “We can do justice to the idea that people are differently situated and that this is exactly what makes public dialogue and collective support necessary” (Sevenhuijsen, 1998b, p. 151). If we attach an care ethics/capabilities-centred perspective to wellbeing in the context of family care, we are able to appreciate the unequal and disadvantaged starting points that empirical evidence has consistently shown some family carers experience and thereby identify family carers as a group that require support and help, never more so than in times of crisis. The sense of abandonment expressed by family carers in this study puts into context what is at stake with carers describing difficult and sometimes dangerous circumstances which can be seen as directly undermining their capabilities to achieve functionings connected to the basics of their everyday lives. In this regard, the pandemic can be understood as an opportunity to critically assess care through a social justice perspective and understand the serious implications of viewing care as a private ‘family’ responsibility.

7.8 SECTION SUMMARY

The inadequacies and failures of support systems for carers are clearly articulated in the extracts provided. Therefore, the sub-theme of support systems dependency is identified and predicated upon the broader theme of vulnerability. The support that carers referred to in this was both familial; based on kinship, and also extrinsic provided by external agencies and both types of support - although identified as essential to the carer well-being, can be understood as creating vulnerability to adverse outcomes both for the carer and by association the cared for and their family.

Identifying vulnerability as a key to understanding negative well-being states is, in contrast, to findings of the carer well-being literature reviews where I identified that well-being as theorised within the broader notion of 'burden'. In the context of care, the burden is assumed as stemming from the caring relationship itself as an individual, familiar and or personal, in origin. The combination of EOC and CA supports identifying the more expansive, structural in origin factors that contribute to carers' negative well-being states.

7.10 CONCLUSION TO CHAPTER SEVEN

The three foundational themes of well-being as multidimensional, freedom and choice and dependency and vulnerability have been captured through detailed and critical thematic analysis of the thirty interview transcripts. The analytical framework adopted and developed throughout the previous chapters has provided building blocks for understanding carer well-being as operating on multiple and complex levels. The first level relates to subjective well-being accounts relating to happiness, self-care, responsibility, and sociality.

The second level of analysis focused on broader socio-political contexts examined through the identified theme of freedom and choice. The argument was presented that structural inequalities limit carer capacity to be free and exercise an option to realise their well-being. The final third level of analysis provided through the theme of dependency and vulnerability connected the previous two levels to the actual achieved or secured functioning's, understood through the self-reported accounts provided by carers. Overall, this analysis extends understanding of how carers experience adverse outcomes and highlights the structural influences that exacerbate and contribute to negative consequences.

CHAPTER EIGHT - CONCLUSION

8.1 INTRODUCTION

In this final chapter, I present the overall findings of the research and reiterate the study question and aims. I demonstrate how and the extent to which the study has addressed and responded to the study's overall purpose. First, I locate the study's overall findings within the broader context in which this study is situated and highlight the novel contribution to knowledge that the research has made. Next, I present a range of specific policy implications arising from the study relevant to national and local policy contexts. A reflection on the study's limitations and ideas on how the study could have been improved and enhanced is provided. Finally, several suggestions from this study for future research are presented and concluding remarks.

8.2 ADDRESSING THE RESEARCH QUESTION AND AIMS

I now refer to the central research question and integrate the main research findings to the research questions and aims.

The study's central research question was:

What is well-being in the context of older age care, and why does it matter?

The study had two main pathways; a conceptual focus on how the idea of well-being operates within the context of care of older people and an empirical emphasis on the properties of well-being that are of significance to carers of older people. Responding to the research question, a series of three sub-questions and aims were developed, and these are presented below along with the main findings:

RQ1. How is well-being understood in the context of family care of older people?
Aim 1. Critically engage with the scholarly and policy literature relating to well-being and care.

The literature and policy review findings were based upon a critical engagement with theoretical perspectives, empirical outcomes, and policy application of well-being within the context of care and are presented in Chapter 2 -5 and are summarised below. A central challenge in responding to the question of well-being in the context of care was the broad and all-encompassing nature of the term itself. Well-being is invoked philosophically, theoretically, and in policy terms as an end in itself and as part of the means of identifying who gets what in terms of social care support. To demarcate theorisations of well-being, emphasis was placed upon tracing the conceptual roots of the concept, and I detailed the major different philosophical and theoretical approaches. This identified the disparate paths of well-being used to explore the implicit values and ideas that impact the current articulations and applications of the term. This theoretical focus also reflected the study's overall critical realist approach; as CR theorist Alderson notes, "The most practical way to begin research is to question its intrinsic theories." (Alderson, 2021,p, 56). Broad analysis reports that the term well-being in the context of family care is undermined by simultaneous neoliberal stress on the primacy of 'responsibility' 'self-care' and 'independence'.

8.3 LITERATURE REVIEW THEORETICAL FOUNDATIONS WELL-BEING - KEY FINDINGS

The main findings based on the literature review show that measures of well-being are individualistic and emphasise subjective well-being features belonging to ideas relating to happiness. I presented an argument that the monistic subjective account of well-being is problematic in relation to carers for the following reasons:

- Subjective well-being measures can mask structural disadvantages. Evidence of inequalities experienced by carers was outlined in the Introduction and examined in further detail in the scoping review of empirical outcomes.
- Subjective well-being denies the importance of fulfilling social relationships in well-being accounts concerning care.
- To connect with others has been overlooked in favour of social-economic rights, e.g., the right to freedom from poverty. In line with Brownlee, I suggest that we cannot flourish or survive without expressing our need to care for and support others (Brownlee, 2020).
- Subjective well-being assigns personal responsibility to individuals for their well-being.

8.4 LITERATURE REVIEW OF CARE THEORY - KEY FINDINGS

Findings of the literature relating to well-being care and older people show an extensive body of work. However, with notable exceptions (Barnes, Taylor, & Ward, 2013), this work has left ideas of well-being concerning care unattended . What is notably absent from these frameworks and, as detailed above, is a political and justice informed account of well-being in the context of older age care, and political philosophy has primarily left this area of research untended (Engster, 2015). From a justice informed perspective, I discuss the implications of this type of conceptualisation to carer well-being in the context of older age care and suggest that it replicates and reflects a specific set of assumptions that result in well-being in the context of care as synonymous with burden and implies three things: 1) Carer well-being is individualised and private and 2) That care of older people is negative and associated with decline, disease and degeneration and 3) That dependency is negative. Work on challenging the active ageing paradigm was identified as particularly salient concerning carers and provided specific insights. In summary, findings show that:

- Family care as the preferred primary means of care for older people is pervasive and can be understood as damaging to carers, particularly women who are caught in ‘double shift’ of working and caring
- Care is a normative concept imbued with ideals concerning family, gender and what it means to grow old
- Family care for older people is theorised from a burden discourse that can be understood to obscure the broader normativity of care and how care is set within differential power hierarchies and needs of carers, in the UK predominantly their need to work centre stage
- Structural inequalities limit carer capacity to be free and exercise choice to realise their well-being.
- There is a lack of work that attends to the situational exigencies that influence caregiving in the context of ageing choices and outcomes

8.5 POLICY ANALYSIS KEY FINDINGS

This stage of the research responded to the research question **1) How is well-being understood and 3) What are the implications of this account?** These questions are considered in turn next.

The policy analysis process generated additional theoretical insights and tested the framework's applicability to policy design (Exworthy, Peckham, Powell, & Hann, 2012, p. 18). Well-being was examined as a 'demonstrator concept', acknowledged and used by the government to determine support arrangements for carers. This was understood to be imbued with political interpretations of what care means and who is responsible for it. The discourse analysis recognises the ill-effects caring can have on individuals but a detachment of government from the responsibilities of care. Relatedly, the idea of choice and individual freedom on which to choose to care were raised, and it is argued that there is a naturalising obligation for families to care. The idea of support for carers through the enactment of the carers assessment can be understood as limited in its capacity to enhance carer well-being. It was suggested that rights are undermined by an individualised account of care and personal responsibility of care. This responsibility was discussed concerning the ideas raised in the literature review in Chapter 3.6 through the concept of 'self-care and 'active ageing.' Social justice questions were raised about the carer's capability to enact self-care practices alongside their responsibilities for care. Finally, it was shown how independence is valorised and how this directs attention away from a conceptualisation of care that recognises relationality and the inevitability of human dependency and vulnerability.

Turning to respond to research question 3; **What are the implication of this account on carer well-being.** It was argued that an 'ageist logic' exists within well-being care policy based on a bio-medicalised notion of older age typified by frailty and dependency. This has led to a policy discourse that valorises maximising independence and presents the need to receive care as unfavourable and contributing to a social burden. On this last point, this study can be understood to contribute to the conception of practical ethics of care (Mol et al., 2011) by developing a critical interrogation of how well-being discourse is deployed and identifying ambivalence and complexity—and highlighting where good intentions may in practice have bad effects (Molterer, Hoyer, & Steyaert, 2019).

I argue that the conception of care and well-being is socially constructed; there is nothing essential or inevitable about the ways we conceive of these things. This is important particularly concerning care because our expectations and experiences of care are primarily determined due to socioeconomic and cultural contexts. These, I argue, can encode oppressive and damaging norms resulting in adverse well-being outcomes for carers. This can result in negative consequences and are not solely derived from the accumulation of subjective burden but are structurally constructed through political arrangements, policy frameworks and shifting family norms.

Furthermore, a broader paradigm that underlines policy formulations of well-being in the context of older age care was identified through 'active ageing.' I suggest that well-being in the context of older age is not confined to the utilitarian, hedonic perspective that valorises economic productivism and 'keeping well' activities. The inherent value of caring as a meaningful practice and as part of human flourishing is presented through these findings. This stands in contrast to the reductive neoliberal active ageing paradigm.

8.6 SCOPING REVIEW OF THE EMPIRICAL LITERATURE – KEY FINDINGS

Through a critical engagement with the theoretical underpinnings of well-being, additional empirical insights based upon secondary data analysis relating to the specific outcomes of care on well-being were identified and explored. These included responding to the identified knowledge gaps pertaining to extrinsic well-being and focusing on dependency and vulnerability. These were identified as critical themes within which carer well-being can be examined. Based on the empirical findings, I suggest an alternative theorisation of adverse carer well-being outcomes that can be understood as a result of increased *risk* to a particular set of *vulnerabilities* to harm rather than a burden. The empirical findings identified in the scoping review can support identifying those carers or factors that increase susceptibility to harm. These are summarised below:

- There is a broad lack of theorisation of carer well-being based upon the burden discourse, mainly focused on understanding depression, anxiety, stress, guilt and anger.

- Positive accounts of care are scarce and theoretical foundations are fragmented, with most studies emphasising life satisfaction or happiness measures.
- The condition of the cared-for are important factors to consider that impact upon subjective well-being
- Cultural values and norms impact carers sense of identity and self-efficacy
- Material aspects of well-being are negatively affected through out of pocket expenses and impacts on employment.
- Carer material well-being is affected by demographic factors such as socioeconomic status, gender, age.
- Evidence relating to material support services to care is experienced as broadly negative.
- Relational well-being has received less attention and studies than other carer well-being aspects.
- The idea of respite and taking a break from the cared-for interacts with cultural norms and expectations of caring for family members.
- The condition of the care receiver, particularly people living with dementia, is significant due to discrimination and stigma resulting in a lack of social connectedness.

8.7 AN ANALYTICAL FRAMEWORK TO UNDERSTAND WELL-BEING IN THE CONTEXT OF CARE

Based on the findings of the theory, policy, empirical outcomes, an analytical framework was presented and responds to Research Question 1, Aim 2.

RQ1. How is well-being understood in the context of family care of older people?
Aim 2. Generate an analytical framework to explore well-being within the context of older age care

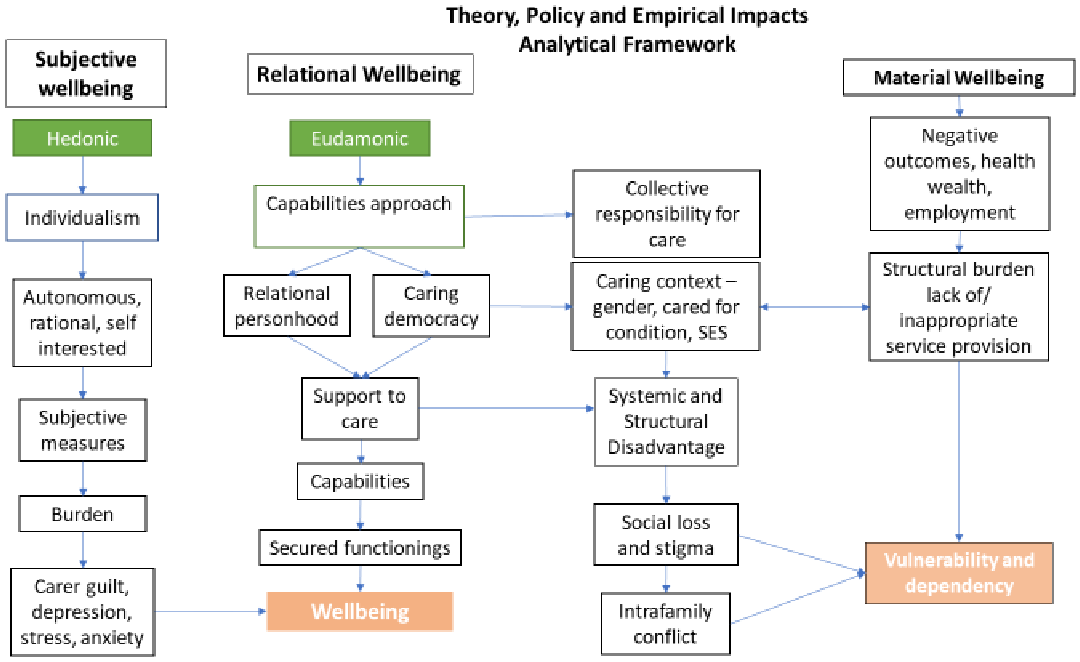


Figure 12 - Analytical Framework

I presented a novel combination of the CA to well-being and the ethics of care approach to care. The merging of the two approaches provides a persuasive explanation in understanding family carer well-being outcomes. The framework demonstrates multiple levels of interconnectivity between individual and relational aspects of carer well-being. The notions of freedom, interdependency, happiness, and responsibility were highlighted.

The argument I presented for the framework is based upon the following claims:

1. **Capabilities Approach A (CA) to well-being accounts for variation in needs and inequalities**

A CA begins by accounting for variations in need; this supports understanding how variations in need can result in systemic inequalities experienced by carers, as Sayer and Wilkinson (2015) state; “We are social beings: that means we are unavoidably dependent on each other in a host of ways, whatever kind of society we live in. That dependence can take mutually beneficial, life-enhancing forms or oppressive, zero-sum, exploitative forms. How can we replace the latter with the former?’ (Sayer, 2018). I argue that understanding inequalities are crucial in raising justice-informed questions concerning the experiences of family carers. The CA originates from a position of social justice recognising that previous attempts to capture a nation’s progress (and also its failure) relied on gross domestic product (GDP); this, as outlined previously, obscures the inequalities that some groups experience despite a seemingly increase in wealth accumulation. This is fundamental concerning population groups such as family carers as Engster notes; “Poverty is overwhelmingly associated with dependency and care.” (Engster, 2015, p. 204). Understanding what carers have reason to value - their outcome, not their means, enables a deeper, more pluralistic understanding of what constitutes well-being for carers.

The CA directs attention to ends rather than means (resources) and assumes a multidimensional pluralistic form of well-being. However, current articulations obscure structural inequalities. Thus, the inequities that carers experience are not accounted for in well-being assessments. This can be understood to entrench further and deepen vulnerability and risk to unequal outcomes.

2. **An ethics of care informed perspective on care enables a collective responsibility for good caring conditions**

An ethics of care approach supplements understanding of carer well-being by recasting citizens as essentially relational and connected, which is in contrast to the individualised rational agent account implicit within a neoliberal discourse. This relational understanding of personhood supports a collective responsibility for care that includes a crucial role for government and statutory providers to provide conditions that nurture 'good caring' arrangements. Furthermore, the politically rooted and broad definition of care supplied by ethics of care theorists Fischer and Tronto (1990) circumvents the inherent problem of carer cared for the dyadic relationship that assumes unidirectionality and obfuscates the agency of the cared for. Finally, an ethics of care approach abstracts the independence from autonomy, and individuals can be independent and experience relational autonomy. Understanding relational autonomy conceived by political and CA theorists (Mackenzie, 2014) overcomes these difficulties.

8.8 PRIMARY DATA FINDINGS

RQ2. Which attributes or properties of well-being are significant to family carer well-being?
Aim. To collect primary research evidence based on carers' views and experiences of well-being.

Empirical insights were provided through this study based upon primary data analysis based on thirty interview transcripts of carers of older people. These findings present new insights relating to how carers of older people view well-being and can be summarised as:

Results show carers of this study view well-being as:

- Multidimensional and relational
- It is more than individual happiness and relates to broader connections with sociality
- It is non-idealised, an imperfect condition, and one that acknowledges decline and dependency as constitutive of well-being
- Care is an essential contributor and constituent of positive well-being
- Extrinsic support is crucial to well-being but is experienced broadly as a contributor to negative well-being.
- States of vulnerability and dependency are articulated throughout all well-being domains.

Carers conceptualise well-being in terms of happiness and ultimately as a subjective state. They also reported recognition of their well-being as intimately bound up with the cared-for (condition and context). This suggests that carer self-reported understandings of care are at odds with policy orientation of care based upon an individualistic conceptualisation of care. Finally, they relate outcomes of care on their subjective well-being characterised as happiness and what is understood in the literature as sociality – a broader eudaimonic conceptualisation of well-being that recognises individuals as inherently social and needing to contribute through care and being cared for. This relational account of well-being has been identified in the gerontological literature, that emotionally rich and fulfilled life in relationships with others constitutes a central prerequisite for well-being at old age (Courtin & Knapp, 2017). This matters to the study because the conceptualisation of well-being articulated within both scholarly and policy literature does not correspond to the experience of well-being for carers. This, I suggest, can be understood to result in policy misalignment and interventions aimed at supporting carers through wellness practices (mindfulness techniques, etc.), but those obscure systemic ways in which carers' well-being can be damaged.

Furthermore, services were reported upon that risked well-being and were even damaging. These findings, in particular, raised critical social justice informed questions. In the context of the pandemic, participants report deprivations of wellbeing that cross material, relational and subjective domains and point not just to matters of concern but matters of injustice. Inequalities have been exacerbated because of the withdrawal of support services, leaving carers alone and without support in many instances putting themselves and the cared-for at increased risk of negative wellbeing states. There is a need for further collection of evidence regarding the costs to unpaid carers of non-recognition and lack of support (Daly, 2020).

Key findings related to vulnerability and dependency (in keeping with scholarly literature) demonstrated that the adverse outcomes experienced due to care are associated with a lack of support, inappropriate support or poor care support. The dependence on systems causes the experience of vulnerability to risk and harm. Moreover, care ethicists have highlighted that many forms of vulnerability are caused or exacerbated by social and political structures (Mackenzie, 2014). I argue that carers are vulnerable to negative well-being states because of their caring role, and this is not intrinsic to the caring role itself but due to the socio-political backdrop, resulting in a negative state of dependency. In addition, relational autonomy theory emphasises that vulnerability can be caused by or exacerbated by social and political structures.

Carers self-reported subjective well-being attributes included identifying a relatively underexplored area of carer well-being relating to positives of care and associated ideas relating to broader social and relational conceptions of well-being identified through the capabilities-inspired approach to the well-being of 'sociality.' The implications of this alternative discourse to care of older people was discussed. Carers understand the caring experience as work (commodified labour) and social value, broader and non-commodified. These ideas were articulated through responses such as; doing good and contributing to society. Relatedly, carers reported acknowledging decline and degeneration and constitutive of well-being accounts.

8.9 THE IMPLICATIONS OF FINDINGS

RQ3. What are the implications of this account of well-being on how family care is understood or family care outcomes?
Aim. Apply the analytical framework to research findings to explore and understand how family carer well-being outcomes can be enhanced.

This study relates to population ageing and sustainable responses to supporting older people in contemporary western welfare systems and is located within the broader 'care crisis' narrative. Care issues are increasingly understood theorised by scholars as critical issues of global significance (Williams, 2018). In the UK, concerns regarding carer inequalities are muted by a mainstream discourse relating to intensified concerns relating to a 'crisis of care'. This crisis is assumed to be borne out of demographic changes resulting in a problematisation of population ageing and older people. Through their associative status as carers of older people, carers as a group are associated with the problem narrative of care of older people, and I suggest that this individualises the responsibilities of care for older people and directs attention away from fundamental questions regarding social justice and responsibility to carers of older people.

Well-being can be used to examine this and is understood as a demonstrator concept used to explore the normative assumptions about care and being cared for in older age. As discussed in the Introduction (Chapter 1) the care crisis debate is broadly theorised based upon the dependency ratio. A zero-sum logic is assumed that if more resources (carers) are supplied into a system, more support will be generated. In this case, the care crisis will be tackled. Relatedly, there is increasing policy attention turning towards providing more employment support to enable carers to combine work and care (Pickard, 2019) and arguments formulated that aim to justify support to carers are typically concentrated on demonstrating the monetary value of care - the cost-saving benefits to NHS and social care systems. These arguments make visible the extent and breadth of unpaid care. However, they do little to dislodge the view that care is equated to neoliberal accounts of citizenship and the underlying neoliberal assumptions of economic productivism. These issues are debated within the apparent 'value neutrality' of policy. Ethical concerns regarding *how and if* carers can combine work and care, rarely enter the debate. Using a CA and care ethics framework can support alternative theorisations and understand family care as a challenge to the idea of care as a commodity (Dowling, 2020; Littler et al., 2020). The findings of this study support these ideas, and I argue that care can be understood based on these claims as universal and necessary for well-being. Therefore, it follows that we have to insist on support for the necessary conditions that develop capacities for all to be able to care in a way that supports functionings.

An exploration of well-being, I suggest, can be understood to offer a challenge to current ideas of care that, as discussed, can be understood as damaging to carer well-being, particularly the idea of burden that reduces well-being theorisation to individual accounts. A reformulation of well-being could replace the concept of burden with the recognition of risk and vulnerability. Well-being is already well established within the social care policy literature – a reformulated and extended conceptualisation of well-being based upon the findings presented above, I suggest could hold much promise in responding to the well-being failures experienced by family carers. At the practical level as well as conceptually, I argue for suitably relational well-being measures that incorporate the extent to which (with the right kind of structural support) care can act as a contributor to positive well-being outcomes and must include acknowledgement of risk and vulnerability to inequalities, and in the context of care of older people must account for implicit ageism (Ayalon & Tesch-Römer, 2017).

The main claims are summarised below:

Overall, the findings presented show that well-being in the context of care supports a theorisation of well-being that is:

- A multidimensional concept comprising of material, relational and objective domains
- An imperfect state that acknowledges vulnerability, decline and dependency
- Well-being is understood as a key functioning or aspect of what it means to live a flourishing or fulfilled life
- The distribution of care responsibilities and its associated risks are experienced differently and correspond to individual and broader cultural and socio-political factors

This implies that:

- Current formulations of well-being based upon active ageing paradigm are reductive and do not capture or reflect the potential of care as a flourishing universal human experience
- That there is a collective responsibility to support good caring relations and conditions
- That underlying inequalities that present risks or potential harm to the well-being of carers must be acknowledged and mitigated to promote sustainable care solutions
- That burden for family care could be understood as risk

In the next section, I highlight the study's contributions to the field before considering the policy implications of the above findings.

8.10 RESEARCH FINDINGS AND CONTRIBUTION TO KNOWLEDGE

The study began with a critical engagement with the so-called 'crisis of care' in the UK. It noted the uneven distribution of care and evidence of substantial poorer well-being outcomes and inequalities that family carers face compared to non-caring population groups. Therefore, the study's overall purpose was to provide conceptual, empirical and policy relevant findings that could support understanding well-being outcomes for family carers of older people. A theoretical framework informed by feminist ethics of care and the CA to well-being was developed. I argued that this framework provided a robust and appropriate explanatory framework to explore and respond to the research question. The coupling of the CA-inspired social justice perspective with the ethics of care approach responds to a growing recognition of the lack of studies that seek to combine an ethically informed discussion of family carer well-being connected to broader socio-political features. I identified a small body of literature that is raising and responding to these questions broadly; "There is little awareness in the gerontological literature of this connection between gerontology and ethics, in particular, relating to the theory of a good life." (Ehni et al., 2018, p. 262). However, there is a paucity of studies that apply the clear idea of a justice informed account of carer well-being and that draw upon primary empirical data based upon carers' views and experiences of their well-being. Furthermore, the findings based upon the literature review and primary data suggest tensions and ambivalence towards the caring role and it is argued that the analytical framework supports understanding these tensions, and contributes to a recognised knowledge gap (Pillemer et al., 2019). The increase in carer inequalities and demand for care, particularly in the context of Covid-19, I argue, amplifies the need for this type of study and inquiry. Furthermore, the primary data findings contribute to a relatively underexplored area of carer well-being that suggests positive contributions that care can make to the well-being of the carer.

This study contributes to current knowledge in the field in the following specific ways; firstly, it provides an alternative and supplemented theoretical account of well-being concerning carers of older people. Identified in the findings through both the literature review and interview analysis is a type of understanding of well-being that is eudaimonic associated with the Aristolean account of well-being virtue. The theorising of well-being from a burden discourse prevents identifying the social or individual salutary outcomes that carers report in this study. As identified in Chapter Two, the positives of care have received little academic attention, and there is a lack of a positive theoretical foundation (Jones et al., 2011). The analytical framework developed in this research enables the identification of the positive contribution that care can make.

Secondly, a contribution to knowledge synthesis is supplied through a scoping review of the contemporary literature relating to family care outcomes. This is the only systematic review that aligns current well-being debates with discussions concerning family carer well-being of older people with secondary data analysis of empirical consequences of care. Thirdly, a novel application of the ethics of care 'Trace Analysis' theorised by Selma Sevenhuijsen was presented in Chapter Four, where the specific policy texts belonging to the Welsh Government and relating to care and well-being were examined. Finally, the study draws upon primary data findings based upon the carer's views and experiences of well-being. Caslini (2020) recently proposed that care ethics can provide a theory of justice not through opposition to traditional forms of the Rawlsian justice model but by using the experience and evidence of injustice as a starting point (Casalini, 2020). An analysis of the primary data from this study demonstrates how carers experience well-being and risks and damages to their well-being. Understood from the capabilities perspective, I focused on structural inequalities to suggest that they limit carer capacity to be free and exercise choice to realise their well-being or 'secure functionings'. Moreover, novel findings were captured during the initial outbreak of the Covid-19 pandemic and, as such, provide accounts on which to understand well-being and threats to carer well-being have been reported upon (Maria & Gideon, 2021; Masterson-Algar, Allen, et al., 2021).

Findings of this study show that the most influential aspect and underexplored aspect of carer well-being relates to what the CA to well-being describes as 'means' – these are the social and political aspects that support the conversion of capabilities into functionings. Service support is a central finding where carers report and negative well-being states. But support to care is also acknowledged as critical to supporting well-being and choice for carers. The policy implications of these claims are summarised below.

8.11 POLICY IMPLICATIONS

In a recent article, Joan Tronto (2017) invites us to think broadly about a different modus operandi for care, one that begins with acknowledging human agents as essentially relational and as humines curans - caring people. Tronto presents homines curans as a challenge and affront to neoliberalism that she, along with other leading political and care theorists, identifies as the biggest impediment to developing a more 'caring democracy' (Tronto, 2017). This study has explored how the value base of well-being can damage and limit well-being outcomes for family carers of older people. In this way, well-being can be understood as a demonstrator concept. Findings based on the well-being analysis in care have evidenced well-being failures relating to a number of features (outlined above in the previous section). The exploration has also supported a type of 'visioning exercise' imagining what an alternative well-being account would need to look for to support positive well-being outcomes. This next section provides a summary of the study findings concerning the applied policy context in Wales.

This study's social care policy analysis was carried out before the Welsh Government's White Paper 'Rebalancing Care and Support'. As such, the study's findings relate to existing legislation and not to the recommendations put forward in the current White Paper (WP). The WP includes proposals to introduce legislation and policy to rebalance care and support to achieve the vision set out in the Social Services and Well-being (Wales) Act 2014. Noted are a discourse for change and better well-being outcomes for all and an emphasis on rebalancing from financial 'price' to quality and value. This aligns with the study's central findings that for many carers, support in the form of statutory interventions is essential for well-being. Still, the study findings show that access to, the process of, and the experience of support result in many negative well-being outcomes. The WG White Paper is a welcome opportunity to tackle these challenges. However, it is noted that while many of the WG strategies are positive, they must be viewed within the broader national (Westminster) government's strategic agenda. Social care arrangements are devolved to Welsh Government, but associated social care welfare support budgets are not. This must be included as a significant feature of the Welsh policy context and how the following policy recommendations are made.

The key policy recommendations made based on the study findings are:

1. ***Promote the principles and associated values of relational care inherent within the feminist ethics of care approach***

Ethics of care informed conceptualisation of well-being stresses the value of interdependence among people and acknowledges the universal need to care and be cared for. Findings from this study show that the framing of well-being for carers around individual rights implies (as described in the findings) that carers aspire to exercise choice 'outside of' their relational situatedness, or independently of it – indeed, that it is something from which they may need to be protected. For carers in this study, their state of well-being is tied closely to the person being cared for. An individualistic model of the nature, scope, and exercising of rights does not easily square with family carers who identify their well-being as contingent upon the person they care for. Similarly, Tronto (Tronto, 2013; Tronto, 2015) argues that democracy depends upon recognition and value of care – but that within neoliberal welfare regimes, care is viewed as a matter of individual responsibility rather than a collective issue (Tronto 2013; 2015). If we accept these views that as humans, we are inherently connected, rather than radically independent, essentially unencumbered rational choice-makers, then there is a need to reformulate the terms on which well-being is understood and recognise the interdependency of caring subjects and the particular impacts of this on how they value and exercise their agency.

Furthermore, the universality of care results in a collective acknowledgment for care and establishing good caring conditions. Recent care ethicists' work has turned to examining the potential of community-based co-operatives as a particularly promising model for care provision (Folbre, 2008). Based upon these assertions, the value of care would take priority over economic gain. In examining these co-operative-based solutions to care, Matthew and Brunsburg (2017) explore a case study example of worker-owned community-based childcare co-operative (Matthew & Bransburg, 2016). This could provide a template for future work to explore community-based cooperatively owned providers for older age care. Incorporating the ethics of care approach of attentiveness, responsibility, competence, and responsiveness could serve to underpin market operations that can be understood to promote the well-being of all those involved in care, including family carers, workers, and the cared for.

2. ***Promote the principles and associated values of a CA to well-being in the context of care***

The foundational concept contained within the CA of substantive freedom is explored and outlined in this study. I suggest that this represents articulating well-being that deepens policy potential to bring positive well-being change for carers. Furthermore, with its focus on what each person can do and be - the well-being outcome, the CA accounts for variations in need and inequalities.

3. ***Review existing tools for measuring well-being outcomes in care that include a CA to well-being and relationality in care***

The CA to well-being draws upon a broad academically informed theoretical base and has been applied across various policy spheres globally. For example, in the UK, the CA has been adopted in the Equality and Human Rights Commission, Equality Measurement Framework, developed by leading CA theorists Tania Burchardt and Penny Lizzard. This framework provides a validated tool that could be adapted to determine the well-being outcomes of family carers of older people (Burchardt & Vizard, 2011).

Using these tools would encourage questions that could provide a transformative policy framework for care; for example, currently, policy formulations are based upon how we can support carers to work alongside care? The study findings show that this assumes productivism founded upon a neoliberal base. Carers reported frustration that they could not lead a life of their choosing beyond work and care. If we reframed these questions from a CA, the question would instead read, "How can we support carers to care and live a life they have reason to value?" Support, therefore, could come in various forms designed to support carers to care as citizens, not workers.

4. ***Gather data that measures well-being outcomes of family carers of older people based upon CA and from a relational perspective***

There is a widely recognised paucity of social care data (Bennett et al., 2020). Based on the study findings, it is recommended that social care data account for variations in need, not just outcome as described above, and draw upon capabilities frameworks for measuring well-being to overcome the inherent problems associated with current formulations of well-being data. For example, rather than 'active ageing,' it is suggested that measures are used that emphasise carers' well-being rather than their production of resources and services (Foster & Walker, 2013).

Having outlined some key policy recommendations, I will now turn to highlight the study's overall limitations before presenting ideas for further research.

8.12 STUDY LIMITATIONS

The empirical findings of this thesis form one part of the overall findings. However, it is important to note the limitations of the primary data results. The findings are based on a sample size of thirty carers caring for older people. As a relatively small sample, it is not possible nor intended to claim any statistical significance for the results. However, the study sample provides a 'concentrating effect' (Wolff & De-Shalit, 2007) in that the findings are based on a sample with specific knowledge relevant to the research questions. I am aware of the limitations of data derived from interviews with study participants, in that participants could tell their story and seek to engage the listener as they are pulled into the teller's point of view (Riessman, 1993), meaning that caution is required as participant narratives are viewed as an offer of a particular version of themselves and events. To overcome this type of methodological limitation, ethnographic studies are often invoked. Ethnography was not suitable for this study as it was not focused on a physical context or intervention. However, future research could draw upon ethnographic methodology to understand how practitioners and carers experience care interventions, for example, the carers needs assessment process and the identification of well-being outcomes generated through mutual negotiating between practitioners and carers themselves.

In addition, a final limitation relates to co-production. As described in the method chapter, co-production is a feature of the critical realistic broad approach. Co-production did not feature in this research, and I identify this as a limitation of the study. Although research participants were asked questions about the research process after the interviews and several participants referred to gaining further support and positive outcomes, the original proposal and budget did not contain co-production aims.

In sum, therefore, and in considering how the study could be enhanced, including data collection based upon the views of policy actors would have offered greater depth and opportunities for comparative analysis between findings based on carers experience and policymakers interpretations. In addition, an ethnographic feature of the study focused on a particular type of intervention would provide insights relating to how well-being as a concept is operationalised ‘on the ground’ and negotiated between carers as clients and users of services and social workers and practitioners gatekeepers and budget holders. Similarly, practitioner views would have significantly extended the empirical base and insights of the study. These ideas, although considered during the research design phase, were omitted due to practical considerations and within the broader context of the Covid-19 pandemic.

8.13 FUTURE RESEARCH

I summarise below a number of ideas for future research and studies that develop and extend some of the aspects of this study.

1. Explore the well-being of carers providing support to older people through alternative co-operatives experience of well-being can be examined within a relatively small nation such as Wales.
2. Use gender relations as an analytical frame, studies that seek to explore the meaning of care for older people from both male and female perspectives and in relation to socio-political arrangements.
3. Devise and pilot a capabilities approach, and care ethics informed carers needs assessment framework. The potential for the framework to be applied to a practical intervention such as the carers assessment would highlight how it could support decision making concerning conflict of rights – the right of the cared-for to choose not to receive care and the right of the carer to receive support to care—a co-produced pilot study that involved carers, families and cared for and local voluntary organisations.

8.14 CONCLUDING REMARKS

I set out to understand the concept of well-being for family carers. Four years on, I feel privileged and very fortunate to have spent time immersed and engaged in a topic of such significance, and one that has maintained my interest and focus. This thesis aimed to contribute to theorising and understanding the well-being of family carers of older people. I have drawn upon the rich scholarly work of ethics of care and capabilities theorists. This work is undeniably theoretically focused; however, I have tried to remain 'grounded' and reflect on how the scholarly theoretical insights translate to carer's lived realities. Through my voluntary role with the local carer's centre, I have listened to the challenges and the charms of living as a family carer. The more I listened and understood, the deeper my commitment to contribute to support and recognition of care for older people, as Lanoix reflects; "The arguments of Kittay and other care theorists go further in thinking about the good; their goal is to change social arrangements." (Lanoix, 2020, p. 47).

I hope that this work contributes to improving the situations for many family carers, and I end this research positive that the more we understand the intricacies, the nuances, the good and the bad of care, the better-caring outcomes for all.

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APPENDICES

APPENDIX 1 – ETHICS APPLICATION FORM

Principal Investigator	Maria Cheshire-Allen
Date	2 January 2020
School	CHHS
E-mail address	[redacted]
Title of Proposed Research	Well-being of Family Carers
Type of Researcher (please tick)	Postgraduate student
Name of course & supervisor	PhD Ageing and Gerontology Professor Norah Keating
Supervisor e-mail address	[redacted]
Qualifications and professional background	MSc Equality and Diversity, Cardiff Uni BSc Philosophy and Sociology, Swansea Uni Researcher at the Centre for Innovative Ageing since 2010. Previous professional roles include policy officer within both NGO and national government offices on ageing and older people related issues.

1. Briefly describe the rationale and the main aims of the research you wish to undertake, including a statement of the intended benefits of the research. Please use non-technical language wherever possible.
Rationale Population ageing is creating demand for innovative and sustainable ways of providing care for older people living at home who need support and across Europe there is an increasing dependence upon family carers to provide essential care services to older and disabled people (Cooney & Dykstra, 2011b; Kodate & Timonen, 2017). A large body of literature spanning several decades demonstrates the negative effects that carers can experience as a consequence of their caring role in areas such as personal, physical and mental health, finances, and social networks (Keating & Eales, 2017a; Pinquart & Sörensen, 2011). In light of population ageing, governments in developed western nations are reconfiguring welfare regimes and in the UK, welfare support programmes have placed family carers central to social care reform policy. In addition, welfare reform policies have been embedded with the concept of ‘well-being’. The precise nature of well-being in relation to family carers has yet to be determined and the concept has been widely examined but is contested and involves deep complexity and lacks definitional clarity (Bache & Scott, 2018b; Devereux & McGregor, 2014; Wallace, 2019). The lack of critical attention to well-being and theoretical framing in relation to

adult social care can make it difficult to identify well-being measures and outcomes capable of enriching policy and practice.

The concept of well-being as a key defining feature of the current social care policy paradigm requires critical attention both in terms of how it applies to family carers in general and its specific significance to a group whom as evidence suggests may be at particular risk of poorer outcomes.

Aim
The overall aim of the PhD is to contribute to understanding of well-being of family carers of older people in the UK, through a theoretical and qualitative analysis of the significance of well-being for family carers. In order to achieve this aim, the following objectives have been identified:

1. Review the empirical evidence regarding the consequences of family care on carers
2. To understand how well-being of family carers is expressed within key family care policy texts of Welsh Government to identify features and conditions of social care policy that could contribute to well-being outcomes for family carers
3. Explore the views and perceptions of well-being and family care with policy makers and family carers
4. Develop an empirically grounded and policy orientated well-being conceptualisation for family carers

2. Briefly describe the overall design of the project including dates and/or the proposed period of investigation

The research conducted will be qualitative and applies a social constructivist grounded theory approach (Bryant & Charmaz, 2007). This approach will guide the theory construction of well-being for family carers. The research will be carried out in three stages and ethical approval is sought for stage three as outlined below:

Stage 1. A systematic scoping review has been conducted of the empirical data on outcomes of family carers and a draft conceptual framework of well-being for family carers has been induced from the empirical findings.

Stage 2. Analysis of key policy texts from England and Wales relating to family care, combining content and discourse analysis. Key themes identified are mapped across to the findings from stage one and a critical inquiry to identify areas where policy reflects or is in tension with the emerging theory of family carer well-being.

Stage 3. Primary data will be collected (upon ethical approval) from Feb 2020 –September 2020. Ethical approval is sought for this final stage of the research project where a series of five interviews and up to 30 semi structured interviews are proposed that will be designed to furnish the theoretical framework of well-being for family carers based on insights from family carers and policy makers. The results from the analysis of the interviews and interviews will input into further refinement of the theoretical framework of well-being of family carers.

3. Briefly describe the methods of data collection and analysis. Please describe all measures

to be employed. If questionnaire or interviews are to be used, please provide the questionnaire / interview questions and schedule.

Data collection

During February through to September 2020 primary research data will be gathered through 30 semi structured interviews family carers of older people.

Theoretical sampling will be used to specify the properties of the tentative theoretical categories of well-being of family carers identified through stage 1 and stage 2 of the research process. These categories are: material, subjective and relational well-being. Each interview will explore one of the three categories and the fourth carers interview will explore issues not covered by the broad categories above. The interview with policy makers will consult on wellbeing broadly as described in Welsh Gov policy and the analysis of the results of the interview discussions with carers.

With written consent, interviews and interviews will be audio recorded, notes will be taken and collection of basic information age, gender, employment status relationship to care receiver and care receiver condition will be recorded **(see appendix 1 – pre-meeting questionnaire).**

The semi structured interviews with carers will be carried out using a topic guide questions and agenda. These questions will serve as prompts to identify ways in which well-being is described and how it is constructed. The semi-structured nature of the interview will allow the researcher to explore and explain the meaning, norms and broad properties relating to certain aspects of well-being for family carers.

Analysis

Detailed transcriptions the interviews will take place and adhere to basic transcription symbols relevant for interviews developed by Jefferson (1984) and modified by (Silverman, 2005). Analysis will be carried out following the constructivist grounded theory approach (Charmaz, 2014) and will seek to identify how well-being is described and the specific attributes or properties of well-being within the context of family care. Emerging sub-themes from stage 1 and 2 of the research process will be used as a coding framework for analysis of transcripts. Transcripts will be selected, coded and organised to ‘fill out’ the properties of the theoretical categories of well-being for family carers. The analysis will identify patterns and clusters of themes that help to explain how well-being is constructed in certain ways; for example words that are routinely linked to ‘well-being’ within social care policy contexts are; ‘health’, ‘independence’ and ‘choice’. This will be triangulated with the analysis of the policy data to explore whether findings from the are reflective or contrasted to the policy discourse and empirical data on well-being of family carers.

The following steps will be undertaken (Charmaz, 2014 cited in Silvernman 2015)

- Initial coding and memo writing of transcript data. Using an iterative process the researcher will compare the data gathered from the systematic literature review and policy analysis to evaluate and adjust the theoretical construct of well-being based on interview data.
- Focused coding will be then used to select key issues and further refine and specify properties of well-being.

- New data will be collected (via theoretical sampling) to further develop categories and properties.
- Further refinement and data saturation until no new codes emerge.
- Refine links between categories, development of conceptual properties and initial draft of conceptualization of well-being for family carers.

4. Location of the proposed research (i.e., Departmental labs, schools, etc)

The semi structured interviews will take place in local carers centres (for example, Swansea Carers Centre, Walter Road, Swansea) and will be identified based on feedback and input from the gatekeeper organisations. This responds to informal discussions and feedback with the local carers organisations that carers need convenient and timely meetings that do not interfere with their commitments and busy schedules (**see appendix 3** for full list of target organisations). It is anticipated that the interviews will be 'bolted onto' already existing meetings that take place within the carers centre such as the carers choir rehearsal so that carers are not unduly burdened by their participation in the interview.

5. Describe the participants: give the age range, gender, inclusion and exclusion criteria, and any particular characteristics pertinent to the research project.

The research is interested in all kinds of relationships which involve care or support and the term carer can mean different things. In line with recent social care legislation in England and Wales something is 'care or support' if the person identifies it as such. A family carer can therefore be someone who:

- Provides a pattern or routine of care or support rather than one-off or very occasional activities, but it doesn't have to be every day, or a minimum number of hours per week, or exactly the same number of hours each week.
- There does not have to be a family relationship between the participant and the person that they provide care or support to. For example, a participant could be providing care or support to a neighbour or friend.

The inclusion criteria for carers is as follows:

- Is able to verbally communicate in English
- Lives in the UK and provides that care or support in the UK
- Has within the past year provided or provides care for an older family member, neighbour or friend over the age of 55 on a regular basis but is not paid to do so.
- Participants do not have to live with the person that they care for or support.

Carer exclusion criteria

- Only provides care occasionally e.g. mowing someone's lawn or taking them to the supermarket
- Under the age of 18

Policy maker

Inclusion criteria

- Currently employed in a policy capacity relating to care
- Works in Wales and is familiar with Welsh social care policy relating to family care
- Able to communicate in English

6. How will the participants be selected and recruited? Please describe in detail the process of recruitment, including how and by whom initial contact is made with participants (e.g. advertisement, e-mail).

Recruitment and selection

The PhD researcher has long standing links with national and local carers and older people's organisation and policy networks; including The Older People's Commissioner for Wales, Carers Wales, the Swansea Carers Centre, Age UK and Swansea Bay Age UK. It is through these networks as well as Swansea University Centre for Ageing and Dementia Research network (CADR) and Health Care Research Wales Involving People network that initial contact for the interviews will be generated. A flyer **(see appendix 4)** will be sent to the organisations to distribute amongst their channels of communication. The flyer will be provided in both English and Welsh although the interviews will take place through the medium of English. It will be made clear to the gatekeeping organisations that a wide range of carers (who fit the inclusion criteria) will be sought, particularly male carers who's views and needs are underepresented in carer research (Calasanti & King, 2007; Greenwood & Smith, 2015).

The flyer is designed to give a brief introduction to the research and to seek expressions of interest. The flyer will contain the contact details of the researcher and potential participants will be directed to contact the PhD researcher for further information. The gatekeeper organisations will also seek permission to pass interested potential participant's details onto the researcher. Upon contact with the researcher, an information sheet **(appendix 5)** will be used to guide the initial conversation and ensure that the participant fully understands the purpose of the research their role within it, issues of confidentiality and consent will be highlighted. It will be reiterated that participants are free to withdraw at any stage of the research process.

7. What procedures (e.g., interviews, computer-based learning tasks, etc.) will be used to gather information from participants?

Participants who have consented to take part in the interview will be sent a pre-group self-completion questionnaire **(see appendix 1)** that will include basic demographic information and an open-ended question relating to 'what well-being means for carers like me?'. The questionnaire will be sent to the individual (via email, post or completed over the telephone) in advance of the meeting. This will enable the researcher to carry out a basic analysis of the group demographics, their views on well-being and identify any emergent themes that could be further explored during the interview. The use of participant responses to the question however will be entirely anonymised, phrases and words will be changed if they are used as a discussion prompt during the interview meeting.

Interview schedule

After participants have been welcomed and introduced to the meeting, the PhD researcher will give a brief overview of the research purpose and format for the meeting (see interview schedule

appendix 2). A series of semi-structured questions and prompts for discussion will follow and the interviews will finish with a debriefing exercise **(see appendix 8)**

8. What potential risks to the participants do you foresee and how do you propose to ameliorate/deal with potential risks? Declare any relationship with the participants.

Confidentiality and disclosure

There is a small risk in interview research that discussions within the interview do not remain confidential or that disclosures are made. The researcher will remind all participants that all identifying information will be removed from audio transcripts and questionnaires. If disclosures are made, the researcher will immediately change the course of the conversation and attempt to head off the disclosure (Bloor, Frankland, Thomas, & Kate Robson, 2001)

Stress and harm

Based on the researchers previous experience of research work, carers are generally happy to discuss and welcome opportunities to describe their situation. However, there could be a small risk that participants may become upset frustrated or anxious during the interviews. In the case of these emotional responses distraction and mood lifting techniques will be used (ibid). Participants will be asked if they wish to continue participating in the meeting and offered a break or withdrawn altogether. The researcher will carry with her a list of local carer support organisations (obtained from the local community voluntary council or carers centre) and offer this information to the participant.

There is a risk that the interview could overrun which could cause stress to the carer who may be extremely time pressurised. A debriefing questionnaire will be handed out to all participants and to allow for private chat with the facilitator.

9. What potential risks to the interests of the researchers do you foresee and how will you ameliorate/deal with potential risks?

Care will be taken to insure researcher's safety. The researcher will not be working on their own with research participants. In the event that participants become upset or stressed at any stage of the research process, the researcher will request to meet with the supervisory team to discuss seek support and debrief.

10. How will you brief and debrief participants? *(Please attach copy of participant information sheets and relevant debrief information)*

Participants will be told about the research at the beginning of the research process (initial telephone discussion) and subsequently sent a copy of the information sheet. Participants will be handed a debriefing sheet at the end of the interview meeting (see appendix 7)

11. Will informed consent be sought from participants?	Yes *(Please attach a copy of the consent form and participant information sheet)*	

Yes. Verbal consent will be obtained during initial telephone conversation with the researcher Written consent (two copies for researcher and participant) will be obtained before the interview meeting takes place	Appendix 5 – info sheet Appendix 7 – consent form	
If no, please explain below:		

12. If there are doubts about participants' abilities to give informed consent, what steps have you taken to ensure that they are willing/competent to participate?
The aim of the research is to include the unpaid family carers of older people. There are no anticipated problems in relation to their ability to give informed consent

13. If participants are under 18 years of age, please describe how you will seek informed consent.
N/A

14. How will consent be recorded?
Verbal consent will be recorded during the pre-interview telephone conversation, and written consent will be obtained through a postal form that will be sent back to the researcher (using pre-paid envelope provided) that will be kept securely by the researcher. In the advent that participants do not return the consent form via post in advance of the meeting, they will be prompted and asked to complete the consent form before they take part in the interview meeting. Two signed copies will be obtained one to be kept by the researcher and one to be kept by the participant. **See appendix 7.**

15. Will participants be informed of the right to withdraw from your study without penalty? If no, please explain why.
The participants will be told of their rights to withdraw at any time throughout the study at the pre-meeting discussion and at the beginning of the interview meeting during welcome introductions.

16. How do you propose to ensure participants' confidentiality and anonymity?
As outlined above, with interview methodology participant confidentiality and anonymity cannot be entirely secured. Discussions that take place during the interviews will be carefully monitored by the researcher and if disclosures are made the researcher will aim to deal appropriately (outlined previously). A unique participant reference number will be attributed to each participant at the first stage of the research process (pre-meeting telephone discussion). All participant data (audio and written) will be anonymised and where appropriate pseudonyms will be applied. Where names and addresses are given (for the purposes of sending out the information sheet and consent form) after the forms have been returned postal address and name will be deleted from the excel spreadsheet.

A researcher fieldwork task list will guide the management of data and ensure all data handling is done in line with regulations and good practice (**see appendix 6)**

17. Please describe the arrangements for storing and disposal of data:
All collecting, handling processing and storing of data will comply with the General Data Protection Regulation 2018 (GDPR). and dispose of in accordance with guidelines after 10 years. Digital information will be stored securely on a secure password protected computer only accessible to the researcher. The data file will be encrypted and password protected. After the interview meetings any personal information will be removed from the excel database, no names or addresses recoded (unless the participant has requested to be kept informed of the research (**see appendix 9).** All written information obtained from individual participants (consent form, pre-meeting questionnaire) will be scanned and stored on the external hard drive kept securely. All interview written information (flip chart notes, post it notes) will be photographed and scanned into corresponding folders kept on external hard drive and kept securely in a locked cabinet in the researcher's office and only accessible to the researcher.

18. Does your research require the written consent of a public or private body, e.g. school, local authority or company? If so, please attach letter of consent.
No

19. If your proposed research is with 'vulnerable' groups (e.g., children, people with a disability etc.), has an up-to-date Disclosure and Barring Service (DBS) check (previously CRB check) if UK, or equivalent non-UK clearance been requested and/or obtained for all researchers?
Researcher has a current DBS certificate

20. Does your research involve the collection of Human Tissue? E.g. saliva, urine	Yes	
	No	No

Applicant's signature: _____Maria Cheshire-Allen________________________ Date: ______29.12.19_______

Supervisor's signature: ____ [redacted] _____________ Date: _2 Jan 2020_________________
(if appropriate)

Upon completion, please forward an electronic copy (as a single document, Word or PDF) by e-mail to **CHHS-Ethics@swansea.ac.uk**
Administrative Support

Research Ethics Committee,
College of Human & Health Sciences
Swansea University
Singleton Park, Swansea, SA2 8PP.

Angela Smith
Research Ethics Committee,
College of Human & Health Sciences
Swansea University
Singleton Park, Swansea, SA2 8PP.
Email: [redacted]
Chairperson
CHHSREC

Pre interview questionnaire

Thank you for agreeing to take part in a interview organised by Swansea University looking at what well-being means for family carers.

Please complete the following questions below and return in the prepaid envelope:

Name
Contact telephone number or email if preferred
Age
Gender
Employment status
Relationship to the person that you provide support or care to
The condition or conditions that the person that you provide support or care to

As a carer (unpaid) for a family, friend or neighbour what does well-being means to you? Please complete using the box below:

Well-being means to me:

Thank you for completing this questionnaire. Please return this questionnaire using the pre-paid envelope provided enclosed to Maria Cheshire-Allen [redacted], Singleton Campus, Swansea University SA2 8PP

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). Any information collected about you will be kept strictly confidential. Your data will only be viewed by the project team. All the information collected will be treated in confidence, stored securely, and accessed only by the researcher and supervisory team.

Appendix 3 - Organisations to approach for support with recruitment for interviews

1. CADR network – awaiting confirmation
2. Wales School for Social Care Network – awaiting confirmation
3. Hafod Care – confirmed
4. Age Cymru – confirmed
5. Age UK
6. Cares Wales - confirmed
7. Carers UK
8. Swansea Carers Centre - confirmed
9. NPT Carers Centre
10. Swansea Bay Age Cymru
11. Older People's Commissioner for Wales
12. Carmarthenshire Carers Organisations
13. Involving People Health and Care Research Wales - confirmed
14. Welsh Government Older People's and Carers Policy Development team

Appendix 4 DRAFT EMAIL and flyer for gatekeeping organisations to distribute

Dear…

As discussed previously, please see request for research participants below for my PhD study 'Well-being of Family Carers'. I would be very grateful if you could circulate amongst your networks and contacts. Just to reiterate the research is entirely voluntary and participants can withdraw at any time. Any information gathered will be anonymised and kept securely. Please direct all enquiries that you may receive about the work directly to myself on the contact details below. Thank you once again for your support and please do get in touch if you have any questions.

Email: [redacted]

Telephone: [redacted]

Request for research participants: Well-being of Family Carers

Well-being for family carers
We would like to invite you to take part in a research project funded by the Wales School for Social Care Research at Swansea University. This research is interested in speaking to people who provide unpaid care (sometimes called informal or family care) for older people (defined as 50 or over) and what they think about 'well-being' and what it means to family carers.

We invite you to take part in a interview meeting with a researcher at Swansea University. During the interview meeting you will be invited to answer and discuss questions about your understanding of well-being. The interview will last approximately one hour and will be organised as much as possible around you. It is expected that the interview could take place at a carers centre close to you. We will discuss the meeting location time and day with you when you agree to take part. Your contribution is entirely voluntary, and you are free to withdraw at any time throughout the research process.

If you are interested in finding out more about the research please contact your local carers centre, or Maria Cheshire-Allen at Swansea University who will speak with you about the project and answer any questions you may have. This should only take a few minutes. [redacted] [redacted]. If you do not wish to take part in a interview but would like to comment on this topic, please feel free to send us your comments either via email or by post. Professor Norah Keating [redacted] Dr Gideon Calder [redacted]

Participant Information Sheet

We would like to invite you to take part in a research project funded by the Wales School for Social Care Research at Swansea University. We are interested in speaking to policy makers who are involved in policy relating to carers who provide care to an older family member, friend or neighbour and what they think about 'well-being' and what it means to family carers. To assist you in deciding whether to take part in this research, we will explain why the research is being done and what it might involve for you. Maria Cheshire-Allen Swansea University researcher will go through the information on the project with you and answer any questions you may have. This should only take a few minutes.

What is this research for?

The purpose of this research is to develop a better understanding of what well-being means for family carers. Results from such research can help to inform policy development and services designed to help family carers caring for someone who is older.

What is my involvement in the research?

The research involves a brief telephone conversation in which the researcher will ask you basic questions about well-being. During the interview you will be invited to answer and discuss questions about your understanding of carer well-being. The semi structured interview will take place in a location of your choosing and last 1 hour. We will discuss the meeting locations time and day with you when you agree to take part. Your contribution is entirely voluntary and you are free to withdraw at any time throughout the research process.

What will happen to the information I give?

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). Any information collected about you will be kept strictly confidential. Your data will only be viewed by the project team. All the information collected will be treated in confidence, stored securely, and accessed only by the researcher and supervisory team. With your consent, the discussions will be audio recorded and notes during made during the interview discussions. Recordings, will be transcribed. Any identifying data will be removed and kept separately and confidentially.

Original audio files will be transferred to University approved computers immediately after the interview and deleted from the recording device. Audio files stored on computers will be destroyed after transcription; anonymised electronic copies of transcripts will be stored on approved University computers, which are password protected and virus checked; these data may be retained for up to 10 years after the study. No personally identifiable information will be kept. Findings of the project will be presented in a final project report for and may be published in academic and professional journals.

If at any time during the study you wish to stop taking part, or you are unable to continue, all of the information collected about you up to that point will be retained and may be used in the study unless you opt out of this on the consent form, in which case all interview information up to that point will be removed and destroyed however interview discussion information will not be removed.

Who is carrying out the research?

The information is being collected by Maria Cheshire-Allen, PhD Researcher, Centre for Innovative Ageing, Swansea University.

Are there any risks associated with taking part?

Research and evaluation undertaken via the college of Human and Health Sciences (CHHS) at Swansea University are looked at by the Research Ethics Committee (REC). The CHHS REC consist of an independent group of people with experience and expertise in research who oversee projects to ensure your safety, rights, well-being and dignity are protected. This project has been approved by the CHHS REC and there are no significant risks associated with participation.

Will the research benefit me?

We cannot promise that the research will benefit you directly, but we hope that by understanding what would help make a decent life family carers we can use this information to inform policymakers

What do I do now?

If you would like to take part in the research, please contact your local carers organisation or Maria Cheshire-Allen, [redacted] Professor Norah Keating [redacted]k; Dr Gideon Calder [redacted]

Appendix 6- Family Carer Well-being Field work task list

Step	Description of step	Associated main tasks	Resources required
1.	Recruitment general	Contact local networks (see list below) national and local organisations with information sheet and flyer. Ask for assistance in snowballing for recruitment.	List of local networks Information skeet Excel spreadsheet
2	Recruitment – participants	Participant contacts researcher - Researcher outlines the project using information sheet as prompt and consent form. - Gather information relating to participant preferred time of meeting and location - Check access/dietary/ other requirements - With consent from participant researcher provides via email/post information sheet and consent form - Create unique participant information number on Excel spreadsheet entry - Make relevant entries in spreadsheet 'Record of key interactions with participants and data management activities'	Information sheet Consent form Excel spreadsheet
4	Pre-meeting questionnaire	- Two weeks before meeting: contact individual participants confirming meeting time and arrangements - email/post/ copy of pre meeting questionnaire and Stamped Addressed Envelope	Standard confirmation letter/email confirming arrangements Pre interview questionnaire

5	Pre-meeting data entry and update	- Update Excel spreadsheet with participant results from pre-meeting questionnaire. - Delete participant personal contact details from database	Excel spreadsheet
5	Interview meeting	Check information sheet received, and all information understood. Obtain signed hard copy of written consent form (2 copies, participant to retain 1) Give participant debriefing sheet and note those who may want to receive eventual copy of research findings.	Consent form Debriefing sheet
6	Post interview data control	Photograph/scan all written information obtained from interview (flip chart notes, post its). Upload onto secure storage. Store all hardcopies of interview data in secure storage (researcher locked office cabinet) Upload audio recording of interview onto secure storage	Data held on researcher encrypted desktop PC and external cloud storage
7	Post research	Send exec summary of research findings to all participants who indicated they would like to receive Delete all contact details of participants who requested to be kept informed.	Research results exec summary

Appendix 7 Well-being for Family Carers Consent Form

As an individual:

I understand that [insert your name] participation in this project will involve:

- Answering questions relating to my situation as family carer
- Participating in a interview discussion where I will be asked questions relating to my experiences as a family carer

I understand that my participation in this research is entirely voluntary and that I am free to withdraw from the research at any time and without giving a reason. If I withdraw from the study, and no further data collection will take place.

I understand that my identity will be anonymised and all information about me kept confidential.

I understand that all information will be stored anonymously and securely. All information appearing in the final report will be anonymised.

I understand that I am free to discuss any questions or comments I might have with either the researcher Maria Cheshire-Allen or the research supervisors Professor Norah Keating and Dr Gideon Calder (contact details below).

I understand that I am free to contact the Swansea University Ethics Committee to discuss any complaints I might have.
I also understand that at the end of the study I and the xxxxxx who took part will be provided with additional information and feedback about the purpose of the study.

I, ……………………………(NAME) consent to proceeding with this research.

Participants signature………………………………………….

Date…………………………………………………PhD researcher:

Email: [redacted]
Research supervisors: Professor Norah Keating [redacted]
Associate Professor Gideon Calder [redacted]

Appendix 8 Well-being for Family Carers - Interview De-briefing Sheet

Thank you for taking the time to contribute to this study. The aim of the study is to develop a better understanding of what well-being means for family carers. Results from such research can help to inform policy development and services designed to help family carers caring for someone who is older. The information you have given me will be held anonymously, this means that it will be impossible for people to know what your answers were.

If you would like to discuss any aspect of the study and your involvement in it, please contact Maria Cheshire-Allen on 01792 295886 or email [redacted]
Research supervisors: Professor Norah Keating [redacted]
Associate Professor Gideon Calder [redacted]

Once again, thank you for taking the time to participate in this study, please let the researcher Maria know if you would like to receive a summary of the final report from this research.

Maria Cheshire-All

APPENDIX 2 – INTERVIEW SCHEDULE

- Encourage participants to set the scene relating to wellbeing and to develop ideas based on the results of scoping review and the application of ethics of care 'trace' approach.
- Looking out for issues relating to multidimensional nature of wellbeing, the processes, outcomes and any trade-offs, particularly given the pandemic. Modes of defining 'the problem', recurrent ways of speaking and judging about family carer wellbeing.
- Ask if participant has read the PIS. Highlight GDPR issues, confidentiality all data is completely anonymised so that no personal information can be traced to participant.
- Check for verbal consent and ask for consent form and gift voucher receipt form to be posted back when lockdown restrictions allow and is considered safe to do.

Introduction – what is the study about?

- Family care is the cornerstone of support for people living with disabilities, chronic conditions and diseases such as dementia. We have a social services and wellbeing strategy that is the legislation that guides all services and support for people with dementia and their carers. So you would have thought that we know quite a lot about wellbeing but we really don't. It really is a slippery idea, hard to pin point.

- **Confidentiality and anonymity** Of course they can withdraw any time during the interview. Also, if there should be a question they do not feel comfortable in answering; they can just tell you "I would prefer not to answer this question".

Do they have any questions for you before you start? Are they still happy with you going ahead with the interview?

Begin recording

- **Can you tell me about you and who you care for?**
  Elicit basic information, relationship to the person cared for, condition of the person cared for, cohabiting, any social support package in place etc.

As you know this research is about wellbeing in the context of family care of older people. I'm going to ask some questions about wellbeing and what you think it means. Please be aware that there are no right or wrong answers and everything you say will be treated in the strictest of confidence.

- When was the last time they felt completely well? Can they describe that situation? Do they feel generally well today?

Material

1. Do they feel caring has an impact on their physical health? How would they describe this impact?
2. How would you describe carer wellbeing overall in terms of your income and resources that you have? Which are most important and why? Not important and why?
3. If the carer is employed: how do they feel about working and providing care at the same time? Does this affect your wellbeing, how?
4. Have they experienced financial implications as a result of caregiving? If so, could they describe how this came about?
5. Has the pandemic affected you in terms of your income, work etc how has this affected you and your wellbeing?
6. What has to be in place to be able to get the things or resources that you need? Individual capacity/social capacity? Who or what can help?

Subjective

1. How would you describe your wellbeing in terms of your emotions or mental health 1) positive 2) negative
2. Could they tell you about positive aspects of caring? What do they get out of caring? What makes caring rewarding?
3. Could they tell you about aspects of caring they find difficult or stressful?
4. Would they say that being a carer for (name of person with dementia) has changed how they feel about themselves? How did it change?
5. How do they draw the balance between the provision of care and their own needs?
6. How important is this aspect of your wellbeing? Are there tradeoffs?
7. How does it compare to the other aspects of wellbeing (prompt)
8. What things can help you achieve positive emotions as a carer
9. What things can prevent positive emotions
10. Has the pandemic changed how you feel, how, why?

Relational wellbeing

1. Would they say that being a carer affects their ability to interact socially (such as meet family and friends, go to social events)? Do they sometimes feel isolated or lonely?

2. How would you describe your wellbeing in terms of the connections that you have with others? Which is most important and why?
3. How important is this aspect of your wellbeing compared to the things you have? Are there trade-offs?
4. What can help this aspect of your wellbeing or does not help?
5. Has this been affected by the pandemic?

Thank them for their time and for sharing their experience with you. Their information is very valuable to help understand better carer wellbeing.

Just to make sure, all the information they have provided will be anonymized and treated confidentially. If they have any questions, they shouldn’t hesitate to contact you at a later date.