

Exploring informal caregivers' health needs from a capability perspective.

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Abstract

Despite more than forty years of informal caregiving research, the health needs of informal caregivers continue to generate considerable scrutiny. Most commonly, caregiving is portrayed as burdensome and a health risk, although positive and ambivalent experiences have been reported. This study uses the Capability Approach (CA; e.g. Nussbaum, 2000; Sen, 1980) as a theoretical framework to add another perspective to the existing literature regarding informal care provision for older people. Participatory principles informed the research, insofar as the participants were accorded flexibility, control, and helped to co-analyse some of the data. Undertaken in New Zealand, the research comprised two studies. In Study One, 60 caregivers anonymously participated in an online research forum, in an evolving joint discussion of their health needs. Template analysis (King, 2012) of the forum postings, based on Nussbaum's (2007) capabilities list, highlighted the relational nature of caregiving and the importance of emotions to the caregiving role. Emotional attachment influenced the caregivers' freedom to choose how they lived their lives, and emotions in general were implicated in the complexities and tensions associated with the caregiving process. An important finding was the self-abnegation of the caregivers who neglected self-care in order to provide care for another. These results led to a second, prospective study that explored in more depth the role of emotions in the everyday lives of caregivers. Six informal caregivers participated in Study Two which involved up to six successive interviews with each participant. Four of the participants kept a solicited diary, which informed the subsequent interviews. Narratives from the second study provided more nuanced data that affirmed the first study's findings, and contributed to the overall finding that an ethic of care underpins the provision of informal care for older people. The participants valued having the capability to care, evidenced by their emotional attachment, attentiveness and commitment to providing competent care. The participants approach to self-care and their own wellbeing was inseparable from the wellbeing of the person being cared-for. These findings have important implications for social policy aimed at improving the experience of providing informal care for older people.

Preface

The social location for this thesis is New Zealand. The data were collected between 2010 and 2013. The thesis is organised around six research manuscripts. The first manuscript has been published in a Special Issue of *Qualitative Research in Psychology*:

Horrell, B., Stephens, C., & Breheny, M. (2015). Online research with informal caregivers: Opportunities and challenges. *Qualitative Research in Psychology*, 12(3), 258-271.

The second manuscript has been submitted to *The Scandinavian Journal of Caring Sciences* and the third paper was published in a Special Issue in *Health Psychology*:

Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. *Health Psychology*, 34(4), 339.

Manuscripts four and five will be submitted in the future.

The sixth manuscript was published in 2014 in *Vulnerable Groups & Inclusion*:

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The manuscripts are presented as published, or submitted, and therefore there is some inconsistency throughout the thesis with regard to referencing styles and language, e.g. a shift between UK and US spelling, due to the different journal requirements.

The ideas presented in this thesis are my own. My supervisors, Christine Stephens and Mary Breheny have provided support through helping me to structure my arguments, strengthen my analytical skills and hone the manuscripts submitted for publication.

For this reason they are included as co-authors on all six papers.

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Next, I wish to thank my supervisors, Christine Stephens and Mary Breheny. It has been a long journey, and I would not have reached the end without your kindness, patience and humour. I hope you never experience another student who tries to read every piece ever written about tangential topics, or falters so often along the way! You have been unfailingly available to dispense your wisdom. Your depth of knowledge and clarity has been an inspiration; I have learned much under your guidance, academically and personally, for which I am very grateful.

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Chapter One: Introduction

The aspects of things that are most important for us are hidden because of their simplicity and familiarity.

Ludwig Wittgenstein

By 2051 older people will make up a quarter of New Zealand's population (Dunstan & Thomson, 2006). Most of these people will require some kind of care before they die. Much of this care will be provided by people who are themselves older people. Current social policy suggests that care for older people will be mainly undertaken in their own homes, informally provided by mostly unpaid family members, friends and neighbours. Government assistance can be expected to continue in some form. Currently, Home and Community Support Services (HCSS) are available in two areas, Household Management (HM) and Personal Care (PC). People qualify for these services based on need, having undergone a needs assessment by a Needs Assessment Co-coordinator (NASC). This assessment is reviewed at least annually and the level of care adjusted accordingly. However, not everyone will qualify for government support and formal home support is considered an adjunct to informal care. Additionally, options for long-term residential care are gradually changing as the focus shifts from long-term to shorter-term acute and hospital level care. Therefore, the responsibility of providing care for our older population falls increasingly on informal caregivers. The provision of informal care raises issues of social injustice and inequality. Informal caregivers for older people are typically women, who are usually unpaid and have no

formal regulatory organisation to protect their welfare or ensure that they are adequately supported in their caregiving role. Informal care may be suddenly imposed without effective choice, adequate financial resources, training, psychological and social support. Furthermore, informal caregiving, often perceived as women's work, is carried out in the privacy of one's home and is therefore invisible to society. These factors all have implications for informal caregivers' physical, emotional, psychosocial, and economic wellbeing. Previous research has identified both negative and positive outcomes of informal caregiving; however, overall the results are varied and many of the same concerns for informal caregivers' health remain after more than four decades of research.

Concern for informal caregivers' health and wellbeing forms the rationale for this thesis; which is organised as follows: Chapter Two provides the conceptual and theoretical background to informal caregiving, while Chapter Three reviews the literature regarding informal caregivers' health. Following Chapter Three I reflect upon my choice of the Capability Approach (CA; e.g. Nussbaum, 2000; Sen, 1980) as the theoretical framework for the study. There are several reflective pieces throughout out the thesis, which are less formal in style than the chapters and papers between which they are interspersed. The CA and Venkatapuram's Theory of Health (2013) are introduced in Chapter Four. Another reflective piece follows the fourth chapter; this time locating myself in the research. References are included at the end of each chapter for consistency in formatting.

Chapters Five, Six and Seven comprise three manuscripts relating to the first study. The first manuscript describes the methodology for this study, and discusses the challenges and successes encountered in using an online forum as a method for data

collection. The second and third manuscripts report the results of Study One, with the second manuscript providing additional detail about the analysis, and focusing particularly on examining the forum posts in terms of Nussbaum's conception of capability in relation to informal caregiving.

Chapters Eight and Nine relate to Study Two. The first manuscript presents the methodology used for this study. It is followed by a manuscript describing the narrative analysis of the Study Two data and presents the results from the study. Chapter Ten combines the data from both studies in an exploration of the intersecting roles of unpaid care and paid employment. The thesis concludes with my final reflections and a formal conclusion. The conclusion sums up the research, points to the limitations, makes suggestions for future research, and discusses the implications for social policy.

Before proceeding, I wish to acknowledge two important points. First, informal caregiving is a social relationship and as such the experiences of all who are involved in the giving and receiving of care for an older person are important. In this study I have made the decision to focus on informal caregivers' health and wellbeing; therefore, all others involved in the caregiving process are only acknowledged in relation to the caregivers. Second, I recognise the heterogeneity of informal caregivers; by gender, race, ethnicity, class, and sexual orientation. I appreciate that not all caregivers have the same experiences, and the inequities created by social policies affect people differently. For some, this is experienced in multiple ways; for example, through their gender, socio-economic status and their ethnicity. This thesis is concerned with experiences of informal caregivers' health in general, and therefore, the participants' experiences cannot be interpreted in terms of socio-demographic or cultural characteristics.

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Chapter Two: Informal Caregiving - Background

There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers.

Rosalynn Carter

Introduction

This chapter is the first of two which provide the background against which to situate the thesis. The chapter traces the history of caregiving research and outlines areas of contestation in the literature around the concepts of care and the definition of caregiving. Next, the reasons why research about informal caregiving for older people has become increasingly important are presented. Finally a description of informal caregivers' characteristics and what caregivers do in the context of care for older people is included. Because of their important roles in the evolution of caregiving research, I have included separate discussions of feminist and the ethics of care literature. As much of the empirical research around informal caregiving has been influenced by this work, these concepts also thread their way through the entire chapter.

An historical overview

Informal caregiving research has been rapidly expanding since the first studies emerged in the 1960s, and Shanas and Streib (1965) put to rest the myth that families were

abandoning their elderly. However, they did identify that families were facing considerable challenges in providing care. This led to the fear that care for older people was in crisis; contributing to a burden of care thesis that has underpinned much of the resulting scholarship around caregiving research. By the mid-1980s a caregiver-burden measurement tool, the Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980), was being widely used and a revised version is still currently used.

Within three decades caregiving had become one of the most researched topics in social gerontology (Nolan, 2001). Feminist social scientists influenced the upsurge in work through their exploration of care as an invisible domestic duty that reflected a culturally imposed, gender-based family role (Rummery & Fine, 2012). This growth in research raised the public profile of caregivers; informing the development of politically active carers' movements as well as social policy and practice (Milne & Larkin, 2015). Throughout the 1980s and the 1990s national surveys were conducted, the effect of caregiving on employment received attention, and national carers' organisations formed in both the UK and America. This steady momentum escalated in line with projections that ageing baby boomers would put pressure on healthcare systems and long term care in particular, as the numbers of people requiring care were predicted to exceed those willing and able to provide care (see Pickard, 2015).

The nature of care

Care has been conceptualised as a disposition and as a practice (Thomas, 1993; Ungerson, 1983). The distinction between these two concepts is commonly referred to as *caring about*, which represents a personal concern for the well-being of another and *caring for* which relates to the physical nature of providing care, sometimes referred to as tending (Parker, 1981). Finch and Groves' (1983) edited book "A Labour of Love" contains a series

of essays exploring the tension between women's traditional roles as unpaid carers and achieving economic independence through paid employment outside the home. As the title suggests care is conceptualised as both labour and love, with an underlying theme that it is also the product of the way that society is organised. Graham (1983) argues that the concepts of *caring for* and *caring about* cannot be separated. It is through caring that women find their place in society; informally in the privacy of their homes and formally in paid employment that exhibits caring characteristics in the public sector.

Graham points out that both love and labour are important components of care, critiquing social policy on the basis that it reduces caring to work, by not recognizing the emotional bonds that constitute care (Thomas, 1993). Much of the subsequent caregiving research has been influenced the conceptual distinction between care as a feeling and care as work (Fine, 2007). For example, Pearlin and Aneshensel (1994) use the term 'career', which is most commonly associated with paid employment, in their model of caregiving, which traces the caregiving trajectory. Arber and Ginn (1999) suggest that although both women and men may '*care about*' women tend to do more of the '*caring for*'. Although working men who care about their family may provide for them in their capacity as breadwinners, they generally perform less of the physical care. It should be noted that it is possible to provide physical care for someone you do not care about, just as it is possible to care for someone, but not provide competent care. In this sense, care provided should be beneficial and do no harm. It is interesting to note that scholars are beginning to advocate for the caring about aspect of care to play a more prominent role in professional health care on the basis that "caregiving is central to what it means to be human" Kleinman (2012, p.1550).

The notion of care as emerging from a familial or social relationship has been developed by Kittay (1999). In response to scholars, mainly from the field of disability studies,

who have suggested that the term ‘care-giving’ implies an unequal relationship through which the person being cared for is dependent upon the caregiver, Kittay has argued that providing care can also place the caregiver in a dependent position because their autonomy is compromised through the acceptance of responsibility. Kittay describes caregiving as dependency work and invokes the principle of *doulia*, whereby the caregiver should be cared for so that they are not penalised by their role.

Spreading the net even wider, Joan Tronto’s definition of care incorporates a range of human activity:

On the most general level, we suggest caring be viewed 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. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.
(Tronto 1993: 103)

These last two views of care, which explicitly identify care as a particular type of social relationship, “and the interconnectedness and interdependence that characterize it” (Daly & Lewis, 2000, p.283) are particularly relevant to this thesis.

Because care emerges from a relationship, family members, especially spouses and partners, tend not to self-identify as caregivers. Often they perceive the care that they provide as a natural extension of a pre-existing relationship. Therefore, in the context of research concerning care for older people, caregiving has been conceptualised as occurring when the person needs help beyond what would normally be expected in everyday life (Walker, 1995). Barrett et al., (2014) suggest that as the level of dependency increases, the meaning of the care provided changes from the caregiver’s perspective.

Feminist scholarship

Feminist scholarship has had a profound influence in the field of caregiving research. Hoyman and Gonyea's (1999) examination of women's experiences in caring for older family members with chronic illnesses or disabilities provides a useful summary of particular feminist concerns, beginning with the recognition that caregiving is invisible to society and therefore undervalued, which is reflected through women not being paid to care at home and being poorly paid for caregiving in the marketplace. They argue that the care provided by women is taken for granted, with little attention directed toward the structural arrangements that create women's dependency and limit their choices, right through to old age.

Hooyman and Gonyea (1999) draw attention to the feminist challenge to these structural inequities, pushing for greater recognition for 'women's work', while at the same time advocating for both men and women to be able to balance caregiving and employment. Acknowledging the inequalities arising from a lifetime of caregiving and the consequences for women's health and economic status in old age, they argue that women should not be disadvantaged by their choices around care and work. Finally, they highlight that a feminist analysis takes account of variations in family caregiving not only by gender but also by race, ethnicity, class, and sexual orientation.

An ethic of care

Ethic of care is a distinct body of literature that originates from feminist psychology (Gilligan, 1982) and locates care at the centre of ethical reflection. Tronto (1993) describes an ethic of care as having four core elements. Attentiveness relates to noticing the needs of others or caring about someone. Responsibility relates to the practical aspect of care, or caring for, and should not be confused with obligation. Competence refers to the provision of good care, in recognition that it is entirely possible to be a caregiver without caring. Responsiveness refers

to the way in which the person being cared for responds to the care being provided. These principles provide a guiding framework for negotiation and reflect an understanding of care as suffusing all aspects of daily life (Barnes, 2012, p.5). Noddings (1984/2013) was the first to make the distinction between the “one-caring” and the “cared-for”. Thus, care ethicists make a point of acknowledging both the giving and receiving of care, and care as relational (e.g. Barnes, 2012; Mullin, 2011). While care is perceived as an intrinsic human value, not only confined to ‘caregiving’, it is an integral dimension of personal and social relationships and care ethicists view caregiving as an activity worthy of public support (Rummery & Fine, 2012).

Care ethicists critique the pervasive assumption that care is women’s work, undertaken only in the private and invisible confines of home. They also question neo-liberal assumptions that people make choices based on their own best interests as opposed to adopting a relational perspective, based on the needs of, and care for significant others. Care ethics thus adopts a relational ontology that conceptualises caregiving as taking place through relationships (Lloyd, 2004). This theoretical perspective is implicit throughout the thesis, complements the theoretical framework informing the thesis, and will be discussed again in the conclusion.

Terminology

Given that the concept of care has so many different aspects, it is not surprising that many different labels and definitions are used to describe the people who provide care. Both the term carer and caregiver are widely used as well as various permutations such as family carer, primary carer, family caregiver, informal caregiver and so on. The term carer is most commonly used in the UK, Australia and New Zealand, whereas it is not generally used in North America. From this point onwards in the thesis, I will use the term informal caregiver, which is sometimes shortened to just caregiver. The term carer will only be used when it is the term used in another author’s work. The term caregiver is based on the following

definition that Goodhead and McDonald (2007) have paraphrased from a more detailed definition in “How Should We Care for the Carers?” (NHC, 1998), which defines informal caregiving as

caring for a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support...[it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations.

I have chosen this definition because of the addition of the final sentence, which is not often incorporated in definitions of informal care in the literature. As outlined above it is a fundamental aspect of informal care. I do not incorporate ‘unpaid’ as an unqualified addition to the definition of informal care because it is no longer appropriate to suggest that all informal caregivers are unpaid. In some countries new measures have been introduced for people requiring care to receive funding to pay for their own form of assistance, as they so choose. Funded Family Care (MoH, 2014) was introduced in New Zealand in 2013. However, it stipulates that the spouse, civil union or de facto partner may not be employed by the person being cared for to undertake their personal care and household management, which effectively excludes a large number of informal caregivers for older people. This is likely to become a serious issue for the future, given the prediction that spousal care is likely to become the main form of care due to population ageing. Additionally, I have chosen the term informal, as opposed to family caregiver because although the type of care that will be discussed in this thesis is mainly provided by family members, this is not always the case.

An important distinction needs to be made between formal and informal caregivers. Formal caregivers who provide community or home-based care receive support and training from a formal organisation, remuneration, and they work set hours. Formal caregivers are

likely to have chosen caregiving as an occupation. On the other hand, informal caregivers may be on call 24 hours a day, seven days a week, without any formal support and their role may have been assumed or imposed upon them (Falchero, 2008).

Caregiving for older people: a topical issue

Like the rest of the world, New Zealand's population is ageing. By 2051, Dunstan and Thomson (2006) predict that the percentage of people over 65 will increase from the current level of 12 percent to 26 percent. Within this age group, the number of oldest-old (people aged 85+) may account for almost a quarter of all people over the age of 65. In 2004 there were 5.5 people in the working-age group to support every person aged 65+. By 2051 this will drop to a ratio of just over 2:1. Given that healthcare needs increase with age, this global phenomenon of an expanding older population, combined with a diminishing younger population, known as population ageing, is a social and economic planning issue. This raises questions about how healthcare will be funded in the future and who will provide the care, prompting scholars such as Kittay, Jennings and Wasunna (2005) to state that we are on the brink of a caregiving crisis.

According to Pickard (2015) demand for unpaid care in the UK will begin to exceed supply by 2017 and the unpaid 'care gap' will grow rapidly from then onwards. On the other hand, Haberken et al., (2012) argue that although the numbers of people in the oldest-old category are rapidly increasing, in other countries the young-old comprise most of the demographic ageing to 2030, and this population will provide much of the informal care for the oldest-old. Regardless, providing care for older people will continue to require careful planning.

Population ageing has coincided with changes in care arrangements for older people (Ansehensel et al., 1995). Historically, the social context for care for older people in Western

society has progressed through phases of home care and institutional care. In Britain, for example, it is only within the last century or so that older people have been distinguished as a separate and distinct group with specific care needs. Previously older people were included in the mass of 'poor' people who were the family's responsibility, or sent to the 'poor house' if they had no family to look after them (Means & Smith, 1998). After the Second World War, institutional settings became the preferred site for care (Thomson, 1983), but this has gradually changed as society has increasingly rejected long term institutional care.

Supporting older people to age in their own home is now considered to be the 'gold standard' for care. This new model supports the notion that people with dependency needs are best cared for in the community by relatives (Means, Richards & Smith, 2008), framing institutional care as inadequate and care at home as preferred. In accordance with international policy, New Zealand's Positive Ageing Strategy promotes ageing-in-place, a political and social imperative that refers to the ability to "make choices in later life about where to live and receive the support to do so" (Ministry of Social Development, 2001, p.10). This counteracts the positioning of older people as vulnerable, frail and dependent (a concept contested by the disability movement); positioning them instead as autonomous agents with the opportunity to choose where they live. This policy facilitates older people's independence and continued participation in community life, if they so wish. This satisfies the preferences of older people who would choose not to live with children or in residential care (Wanless, 2006). Taken at face-value, this shift in the location for care appears to meet the needs of older people and policy makers alike. However, critical scholars (see Asquith, 2009) question the impact of neoliberal policies, such as those introduced under the auspices of positive ageing, which idealise individual autonomy and independence, yet are driven by economic priorities.

Deinstitutionalisation is predicated on informal caregivers' unpaid assistance and

support, to the extent that Heaton (1999) has suggested that we are now experiencing care in the community by the community. Taking for granted informal caregivers' availability and willingness to provide care raises several issues. Sociodemographic factors are changing the nature and extent of family networks. Family sizes are falling, due to decreasing fertility rates, and the choice to remain childless (Fine, 2007), and children have become more mobile, or geographically dispersed, which make them less able to provide care (Barrett, Hale & Butler, 2014). Higher divorce rates and re-marriage may reduce contact between generations due to decreased co-residence, relationship quality and reduced contact with adult children (Glaser et al, 2006). Additionally, more women are working outside the home and are therefore less available to care (Fine, 2007). Working women either have to juggle part-time work and unpaid care, or are unable to provide care. Tighter assessment standards and a shortage of places in residential care facilities reduces options for those unable to provide care, putting pressure on family members and friends to provide care at home (Barrett, Hale & Butler, 2014).

Since the late 20th century, policy makers have increasingly focused their attention on the financial burden of providing services for older people, including long term care (Purkis & Ceci, 2014). Because community care is associated with reducing or delaying the uptake of residential care (Gibson & Houser, 2007), policy makers and health care providers rely upon informal caregivers as a means of reducing costs in the health care system. As a result, there has been a tendency in the social policy and economic literatures to view caregivers as a resource, rather than as participants in a caring relationship. For example, Spillman & Long (2009) recommend initiatives to reduce caregiver stress as a promising strategy to avoid or delay residential care for older people. However future research should focus on maintaining the health and well-being of informal caregivers because their health is

important, not because it keeps others out of residential care and reduces the financial burden of elder care on the state. Furthermore, policy analysts have paid insufficient attention to the ways that care, as a concept, benefits the whole of society, not just individuals (Barnes, 2012).

The prevalence of informal caregiving for older people

The information in this section relates to the local New Zealand context. Generally, this is consistent with international trends and statistics. According to the 2013 Census data (Grimmond, 2014) just over 430,000 adults were looking after a household member or someone outside their household who had an illness or disability. However, these figures relate only to the previous four weeks, with no indication if this was short or long term care. In total, the census identifies 12.8 percent of the adult population of New Zealand as unpaid caregivers. The 50-54 year age bracket comprised the largest group of caregivers, who would fit into the midlife age group, identified in the international caregiving literature as ‘sandwich carers’, because they provide care for their parents as well as supporting their children (Fingerman, 2010). Support for children may also extend to providing care for grandchildren (Ben-Galim & Silim, 2013). In 2006, 30 percent of all caregivers were aged 55 and over (Department of Labour, 2011).

Disabled adults in the 85 and over age group are the most likely of all age groups to get help from informal carers, and just under a third of women aged 75-84 were living with a spouse or partner, which raises questions about who will provide care for the large numbers of un-partnered women as they age (Office for Disability Issues and Statistics New Zealand, 2009). In a more recent report, Grimmond (2014) identified that unpaid caregivers in New Zealand are twice as likely to be female as male; older than the typical New Zealand adult, with their median age increasing at a faster rate than the national average; and from all ethnic

backgrounds, although Europeans and Māori have a higher propensity to undertake family caregiving. Grimmond also states that the average family caregiver devotes 30 hours per week to providing caregiving services every week of the year, which equates to more than one-quarter of their waking time.

Internationally, most informal care for older people is provided either by their children or by their spouses or partners (Pickard, 2015). These caregivers mainly comprise the young-old and the old demographic groups. Schofield et al.'s profile of Australian caregivers (1997) found that the largest caring group were adult offspring, who were mostly daughters, caring for parents. This was followed by people, mostly older wives, who were caring for a spouse or partner. Studies consistently suggest that around two thirds to three quarters of informal caregivers for older people are women (e.g. Lee & Porteous, 2002; Scharlach, 2008).

As well as providing care to frail relatives, partners and parents, an increasing number of grandparents look after grandchildren and support working mothers and fathers. Although currently more children provide care than spouses or partners, this may change in the future. The projected improvements in male mortality suggest that the number of widows will decline, hence the proportion of spousal or partner caregivers may increase. Further, it has been suggested that the increase in care provided by spouses and partners may go some way towards compensating for the potential decline in care by children (Colombo et al., 2011).

What informal caregivers do

The type of care provided by informal caregivers varies, and has traditionally been separated into two categories, Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The former refers mainly to personal care or self-care activities such as toileting, bathing, dressing, eating and monitoring medication, and the latter to the

practical tasks that may not be considered essential for daily functioning but enable people to live independently. This includes helping with housework, meal preparation, and shopping (including assistance with transportation). For some, this also includes home maintenance and gardening. Distinguishing between these two types of care has implications for caregivers' self-identification. Someone who assists with IADLs is less likely to consider that they are a caregiver than someone who assists with ADLs. Yet, assistance with IADLs often enables the person being cared for to remain living independently at home, which Hale, Barrett and Gauld (2010) describe as supported independence. In this way, the illusion of independence is maintained by the person being cared for while rendering the assistance from informal caregivers as invisible, and therefore less likely to receive support via public policy.

Informal caregivers also provide support in terms of companionship and surveillance for those with cognitive impairments. This involves being available to ensure the safety of the person being cared for, for example in case of falls, or wandering that may be due, for example, to dementia. It also includes worry and planning associated with caring *about* someone, which is often less well acknowledged. Moreover, contemporary informal caregivers are frequently caring for older people with high levels of disability. For example, caregivers are being trained to give injections, manage catheters and incontinence, monitor and administer medication, and change dressings, all of which used to be carried out by trained nurses (Barnes, 2012).

Chapter summary

This chapter has provided some context for the informal provision of care for older people. Starting with an historical overview of the caregiving literature, and feminists' contribution to this body of work in terms of conceptualising the nature of care and the subsequent influence this has had on caregiving research, the review moved on to a discussion

of the current extent of informal care and concluded with a description of informal caregivers and what they do. It is interesting to note that after more than thirty years of informal caregiving research, many of the original concerns of the early feminist scholars remain. Although women's caregiving is more widely recognised and valued, payment for caregiving remains an issue. Additionally, the concern for a work-care balance has evolved into concerns regarding women's management of work, care and life and choosing to provide care only is a less well supported option. Accordingly, in the next chapter I will concentrate on the impact of caregiving on informal caregivers' health, which is the focus of this thesis.

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Chapter Three: The effects of informal caregiving

Care is fundamental to the human condition and necessary both to survival and flourishing.

Marian Barnes.

Introduction

In the following review of the informal caregiving literature I have organised the findings into three main categories entitled burden, benefit and equivocality. The order reflects the trajectory of caregiving research; early studies focused mainly on the negative consequences of caregiving, and it is only relatively recently that the positive, and latterly the ambivalent, aspects of caregiving have begun to appear in any quantity. Caregiving experiences substantially overlap in the different contexts for caregiving; therefore, some of the findings in this review pertain to caregiving in general. I have specified where the findings relate specifically to informal caregivers for older people. Following this review of the literature, I discuss the ambiguity of the overall findings and conclude the chapter with a discussion of the different types of support for informal caregivers and their effectiveness.

Burden

The informal caregiving literature is multidisciplinary. For example, studies have been undertaken in psychology, family studies, nursing, sociology, medicine and gerontology. The definition of caregivers' health varies in the literature, and includes physical symptoms and psychological measures of well-being or quality of life. This definitional variation complicates our understanding of the overall impact of caregiving

(Saban, 2010). However, much of the literature regarding informal caregiving for older people demonstrates the negative impact, or burden, associated with providing care. The term ‘caregiver burden’ is a psychological concept (Purkis & Ceci, 2014) and came into widespread use more than thirty years ago when Zarit, Reever, and Bach-Peterson (1980) created the Zarit Burden Interview to measure the strain experienced by informal caregivers for a relative with dementia.

Caregiver burden has been studied extensively, both as a predictor for poor health and as an outcome of the caregiving process (Savundranayagam, Montgomery, & Kosloski, 2011). Research framed this way indicates that caregiver burden negatively influences the physical, psychological, psychosocial, social, and financial health of caregivers (Feinberg et al., 2011). However, the consequences of caregiving have usually been measured in terms of psychological or emotional health such as depression or ‘caregiver strain’ (O’Reilly et al., 2008). Caregiver burden has been conceptualised as a “model of chronic stress” (Vitaliano et al, 1997, p. 117), with research consistently indicating that women and those who live with the person being cared for experience higher levels of stress (Yee & Schulz, 2000). This is reflected in Opie’s (1992) qualitative study of caring for older people with dementia, which found that all of the caregivers suffered from chronic exhaustion and most of the older caregivers had some physical illnesses. The results from two New Zealand surveys of older people in 2010 and 2012 indicate that caregivers experience poorer health as their level of care provision increases, highlighting the association between caregiver burden and physical health (Alpass, Stephens & Stevenson, 2013).

Physical effects

In comparison to noncaregivers, caregivers report worse physical health and

take more medications (Legg et al., 2013; Vitaliano et al., 2003). A seminal study undertaken by Schulz and Beach (1999) that identified caregiving as a risk factor for mortality generated a plethora of research that investigated the relationship between caregiving, strain, and mortality. For example, a meta-analysis of 84 studies comparing the differences between caregivers' and noncaregivers' psychological and physical health, found a small but significant effect in relation to physical health, with caregivers experiencing poorer outcomes than noncaregivers (Pinquart & Sörensen, 2003). In a later meta-analysis of 176 studies, the same authors (Pinquart & Sörensen, 2007) found that older caregivers, those with lower socioeconomic status, and caregivers with lower levels of informal support were most likely to suffer poor physical health. They also found a difference between the predictors for adverse physical and psychological outcomes and that the negative effects of caregiving on physical health are most likely to be found in psychologically distressed caregivers facing dementia-related stressors. This suggests that the interaction between psychological and physical health is an important component in our understanding of informal caregiving for older people.

Physical stressors such as sleep disturbance, fatigue and back injury are commonly reported (Rubin & White-Means, 2009), and in a study of older people with poor memory, Chumbler et al. (2003) report 22 percent of caregivers as saying their health was fair to not good at all and 30 percent reported high blood pressure. Locally, Campbell's (2004) qualitative study of four rural women in their 60s who were caring for their terminally ill partners highlighted caregivers' self-neglect, due to the time pressures of caregiving. While the negative physical effects of caregiving are widely reported, these are generally smaller than for psychological effects.

Psychological and emotional effects

Caregivers consistently report negative mental and emotional health consequences from caregiving. In many studies caregiving is associated with increased rates of depression and anxiety, less life satisfaction and a feeling of being burdened. The largest differences between caregivers and noncaregivers relate to depression, stress, and self-efficacy, with informal caregivers of people with dementia showing higher levels of psychological distress than caregivers of physically frail older people and non-caregivers (Pinquart & Sörensen, 2003). Caregivers providing care for someone with dementia were most at risk from depression. In Fisher et al.'s (2011) study almost 40 percent of family caregivers for older adults with cognitive impairment or dementia reported poor psychological health and 70 percent reported emotional strain.

Hirst (2005) provides convincing evidence of the negative effects of informal caregiving on mental health. His study showed that caregivers providing 20 or more hours of care per week risked twice the amount of psychological distress as noncaregivers. This effect rose with increasing hours of caregiving and was greater for women, which is consistent with other studies (e.g. Alpass et al., 2013; Cannuscio et al. 2002; Pinquart & Sörensen, 2003). Hirst found that adverse psychological effects for heavily involved caregivers are most pronounced when caregiving starts and ends. Vitaliano et al.'s (2003) meta-analysis of the impacts of providing care to dementia patients found twice the rate for major and minor depression among caregivers compared with non-caregivers, which supports previous findings that caring for someone with Alzheimer's is strongly associated with worse mental health for the caregiver. These findings are significant given that depression and stress is linked to increased mortality for older people (e.g. Adamson et al., 2005).

Living with the person being cared for is an important factor associated with adverse mental health. For example, spouse caregivers report more depression symptoms and lower levels of psychological well-being than adult children and children-in-law providing care, who are less likely to co-reside (Pinquart & Sörensen, 2003).

Additionally, caregivers' quality of life may also be affected by co-residence. Statistics from a recent UK survey state that co-resident caregivers are twice as likely to report social isolation because they are unable to leave the house. Overall 83 percent of carers have felt lonely or socially isolated and 57 percent of carers have lost touch with friends and family (CarersUK, 2015). In a New Zealand study, Opie (1992) reports that the caregivers in her study (who were caring for someone with dementia) felt isolated because they had not been able to keep up with social and leisure activities outside the home. This loss of social contact with others is concerning given that social isolation has been identified as a mortality risk (House, Landis & Umberson, 1988). A more recent study found that less than four percent of New Zealand caregivers for older people were happy with the support they received while providing care and 62 percent of caregivers aged 80 to 89 showed signs of depression (Jorgensen et al., 2010).

Financial effects

Caregiving is associated with adverse financial impacts. These take the form of lowered income because of reduced or relinquished employment coupled with higher costs arising from care-related expenses such as increased heating, medical costs, transport costs and house modifications (Goodhead & McDonald, 2007). Recent UK research (CarersUK, 2014) has identified that almost a half of caregivers are in debt and cutting back on essentials like food and heating to make ends meet; and 53 percent of all caregivers report their financial circumstances are affecting their health. A meta-analysis conducted by Pinquart and Sörensen (2011) found that spouse caregivers report greater financial burden

than adult children and children-in-law. Additionally, a study conducted by Wakabayashi and Donato (2006) indicates that relinquishing paid employment poses a risk to women's economic wellbeing in later life. Recent New Zealand figures identified that in 2013 the households of unpaid caregivers typically earned ten percent less than households without caregiving responsibilities (Grimmond, 2014). Fewer hours of paid employment appears to be an important factor. Despite caregivers having a similar propensity as noncaregivers to be in paid employment, to be qualified, and work in higher skilled occupations, they were more likely to be in part-time employment and to be eligible for some form of benefit.

Effects on employment

Simultaneously managing paid employment and informal care can involve practical and emotional challenges, which can lead to caregiver strain (Fredriksen-Goldsen & Scharlach, 2006). Providing care for older people produces more strain than childcare, particularly when living with the person being cared while working outside the home (Duxbury, Higgins, & Smart, 2011). Both Latif (2006) and Milne et al. (2013) found that caregiving negatively affects the hours people can work, with women more likely than men to give up paid work. This supports Kotsadam's (2011) findings that caregiving for older people negatively affects women's employment across the European Union. Similarly, Fast, Dosman, Lero and Lucas (2013) found that caregivers more at risk for care-related employment consequences are women, men caring for a spouse, those approaching retirement age, those in poorer health and people spending more time performing care tasks. Caregivers use various strategies to try to maintain both paid employment and caregiving, including changing to a less demanding job, and using holiday or sick leave for caregiving purposes (Goodhead & McDonald, 2007). In this respect, research unequivocally demonstrates that employees value working for businesses that provide assistance which

helps them cope with caregiving demands (Calvano, 2013).

On the other hand, employment helps to maintain social networks, which benefits emotional wellbeing (Arksey & Glendinning, 2008) and provides respite from the caring role. Being able to engage in paid work enhances self-esteem and provides opportunities for talking with workmates which helps to ease the burden of caregiving (Arksey 2002). In New Zealand, caregivers do not appear to receive lower incomes because of a lower skill set than non-caregivers (Grimmond, 2014). Rather, they typically have a higher propensity to be employed in higher skilled occupations. This suggests that New Zealand caregivers are not penalised in terms of their occupations. It seems that the factors affecting their earning capabilities are that most caregivers are women, and women are more likely than men to be working part-time, despite their skills and ability. Determining cause and effect in this situation is difficult. For example, women working part-time, may be the 'obvious' choice to take on caregiving duties when required. On the other hand, needing to provide care may preclude full-time work.

Benefit

While research has reported the negative effects of informal caregiving, caregiving can be a positive experience (Zarit, 2012). Despite the demands of caregiving, most caregivers feel positive about giving care and are happy to be in that role; however a much smaller literature attests to the benefits of giving care compared to literature concerned with the burdens of caregiving. This is hardly surprising, given that the burden literature arose from a concern for the health and wellbeing of informal caregivers. An early study by Kinney and Stephens (1989) looked beyond the stressors in caregivers' lives to include positive events, which they called 'uplifts'. The following year, Pearlin, Mullan, Semple, and Skaff (1990) introduced measures of gain and competence, believing that in stressful

circumstances people can experience inner growth.

Acquiring specialised knowledge and skill, personal growth, life satisfaction, and enhanced family relationships, have all been identified as positive aspects of caregiving (Carbonneau, Caron & Desrosiers, 2010; Post, 2007; van Durme et al., 2012). Nolan et al. (1996) have identified that a sense of giving back relates to higher levels of subjective wellbeing and in an analysis of the Canadian Study of Health and Ageing, Cohen, Colantonio, and Vernich (2002) found that more than 70 percent of caregivers were positive about their caring role, citing the benefits of companionship, fulfilment and reward. Similarly, Brouwer et al. (2005) found that informal caregiving can be an important source of happiness in people's lives, as long as they remain in control of the process. Egbert et al. (2008) found that 69 percent of caregivers reported very good or excellent health in the preceding month. This supports Brown et al.'s (2009) study of older married caregivers, which reported that giving support to others may reduce mortality risk. They also cite evidence of beneficial health outcomes from studies of volunteering and social support (e.g. Brown, Consedine & Magai, 2005; Pinguart, 2007; Post, 2007) stating that the contradiction between these and previous studies of caregiver burden is "a paradox that begs for empirical clarification" (Brown et al., 2009, p. 489). Attempts to clarify this paradox are described in the following section about ambivalence in caregiving.

Ambivalence

As well as studies documenting the positive or negative effects of informal caregiving, evidence of caregivers' ambivalence is emerging, demonstrating that stresses and satisfactions can coexist, especially in studies concerned with the multidimensional aspects of caregiving. Ambivalence has been defined as 'simultaneously held opposing

feelings or emotions that are due to countervailing expectations about how individuals should act' (Connidis & McMullin, 2002, p. 558). Hillcoat-Nallétamby and Phillips (2011) use the concept of sociological ambivalence to explain the complexity of informal caring in the context of ageing parents' transition to dependence on their adult children. They describe the tensions, shaped by sociocultural arrangements, as adult children negotiate their parent's increasing demands on their time while attempting to maintain their own independence.

McKee et al. (2009) have developed a new instrument, the COPE Index, to assess multidimensional concepts such as ambivalence in caregiving. The aim of the index is to identify caregivers' needs. However, it moves the focus away from burden and the objective, everyday problems of the person being cared for, and onto the caregiver's subjective perceptions of their circumstances, relationship with the person being cared for, and of the quality of formal and informal support. A caregiver may record different scores on the different dimensions, thus reflecting the complexity of caregiving. For example, a caregiver may feel stressed, but gain satisfaction from his or her role and may strongly wish to continue if the quality of support can be improved. Balducci, et al. (2008) believe that this index will aid in understanding the complexities of caregiving in a way that has not been previously possible.

In their study of spousal caregivers for a person with dementia, Shim, Barroso and Davis (2012) identified three discrete types of experience; negative, ambivalent and positive. The caregivers whose experience was negative were focused on their unmet needs rather than their spouses' needs and reported significant caregiving burden. The caregivers who experienced ambivalence lamented a lost, reciprocal relationship with their spouse, but derived satisfaction from giving care; and the positive caregivers

focused on the positive aspects of the relationship they still had, expressing satisfaction with caregiving and expecting nothing in return. They were focused on their spouse and not highly burdened by caregiving.

In a different context, Igarashi et al. (2013) describes mixed emotions of joy and burden experienced by caregivers simultaneously supporting young adult children while providing care for ageing parents. They found that midlife parents expressed less ambivalence around helping children build independent lives compared to providing care for older parents. They conclude that these differences are best understood through “the cultural ideal of independence and autonomy and its dialectic with interdependence and dependence” (Igarashi et al., 2013, p.110). Thus, Connidis and McMullin’s (2002, p.565) conceptualization of ambivalence as “socially structured contradictions made manifest in interaction” appears to aptly describe the context for giving and receiving care. The tension between individual autonomy and family responsibility can be ongoing, with the negotiation of ambivalence reproducing the status quo or acting as a catalyst for change at the individual, family, or societal level (Connidis, 2015). This is reflected in Dunér’s, (2010) study of caregivers helping older Swedish relatives. She found that caregivers, mainly daughters, often pushed for more formal help, which had previously been denied from formal services or rejected by the person being cared for, to lessen their own caregiving input.

The preceding findings illustrate the propensity for informal caregivers to experience caregiving as negative, positive and ambivalent when providing care for older people. Connidis and McMullin (2002) state that compared to men, women have limited options with respect to giving care to family members. They argue that gendered expectations place pressure on women to manage caregiving alongside other

commitments while at the same time being expected to derive pleasure and satisfaction from caregiving. According to Connidis and McMullin (p.265), “individuals experience ambivalence when social structural arrangements interrupt their attempts to exercise agency when negotiating relationships, including those with family members”. They suggest that people with fewer options or choices available to them are more likely to resolve ambivalence through acceptance rather than confrontation.

Equivocality

This review of the informal caregiving literature illustrates that studies comparing the health and wellbeing of caregivers and noncaregivers are inconclusive. This may be attributed to several factors. Van Groenou, de Boer and Iedema (2013) suggest that different types of care relationships and individual differences may explain contradictory experiences. Alternatively, differences in research design may produce different conclusions. Ramsay et al. (2013) argue that variations in caregiving definitions affect comparisons between studies, whereas Brown and Brown (2014) suggest that dissimilar methodologies make it difficult to draw any consistent conclusions about the state of informal caregiving. Most informal caregiving research acknowledges methodological difficulties in determining whether caregiving in itself causes ill-health (O’Reilly, 2008). These include the inability to compare different dimensions of caregiving, insufficient control for possible confounders, small sample sizes, and purposive sampling as examples of methodological limitations.

In terms of sampling issues, Schulz et al. (1997) note that recruitment through official services may include a disproportionate number of stressed caregivers, leading to possible overestimation of negative health outcomes. A major methodological and conceptual limitation of caregiving research is the extensive use of cross-sectional studies

that cannot capture the longitudinal and dynamic nature of caregiving (Beach et al., 2000). They argue that over time, caregivers change the way they care to accommodate the changing needs of the person being cared for. Consequently, caregivers may engage in very different care behaviours, thus experiencing their roles differently at different points in caregiving trajectory (Montgomery & Kosloski, 2013). Understanding caregiving as a dynamic process is essential in terms of designing effective strategies and resources for supporting caregivers.

Support for caregivers

Although the extent of caregiver burden has been contested (Brown & Brown, 2014), the research focus on burden has stimulated the development of interventions such as counselling, support groups, training and respite care as coping strategies for caregivers. Counselling appears to impact positively on self-rated health (Mittelman et al. 2007), and Droes et al. (2006) report that integrated programmes of support are effective in terms of alleviating stress and delaying care home admission. However, Milne et al. (2013) state that despite carer support groups' popularity, they are mainly only effective in terms of psycho- educational groups for those providing care for people with dementia. Marriot et al. (2000) highly rate the provision of information; for example regarding services, and how to manage challenging behaviours. Practical help with the physical aspects of care, such as incontinence, is valuable and caregivers providing intensive care appreciate good-quality respite care (Arksey & Weatherly, 2004). It appears that caregivers would benefit from these types of support; however interventions are often not well utilised (Di Rosa et al., 2011; Foster, Layton, Qualls & Kebe, 2009; Montgomery & Kosloski, 2013).

Molyneaux et al. (2011) note that many caregivers remain disadvantaged by

caregiving, and question the effectiveness of existing services. Various reasons have been offered for their limited use by caregivers, including limited knowledge of services, difficulty accessing services, and reluctance to accept help, particularly when it comes to entrusting loved ones' care to strangers (Hooyman & Kiyak, 2011). Montgomery and Kosloski (2000) suggest that services are inappropriately matched to caregivers' needs; while García-Alberca et al. (2012) state that those most in need of help are likely to disengage from sources of social support. Nolan et al., (1996) describe the acceptance of support as a balancing act, whereby caregivers weigh up the benefits for themselves against the drawbacks for the cared-for person, and feelings of guilt for relinquishing care, albeit temporarily. Glasby et al. (2010) describe caregivers as feeling overlooked and having to fight bureaucracy to receive the support they need. These issues likely arise because assistance is mostly provided as an institutional universal service that neglects the social context for caregiving (Brown & Brown, 2014).

New Zealand has a formal system of benefits and services intended to support older people to age independently in their own homes. Social services are needs-tested, based on specific criteria and they are funded from taxes and administered by regional District Health Boards who call for tenders from private companies to provide home support services. The resulting provision of formal home care is often discussed as a remedy for informal caregivers' burden, but the in-home supports offered are mainly for the person receiving care, such as bathing assistance, rather than targeted support for the caregiver (Keefe et al., 2008). In the international literature, the effects of formal home care on informal caregivers are considered to be mixed (Zarit & Femia, 2008) and there is evidence that informal caregivers do not relinquish the care giving role when publicly paid home care becomes available (Li, 2005). Stoltz, Lindholm, Udén and Willman

(2006) argue that support should meet caregivers' particular needs, which requires strengthening the relationships between caregivers and health professionals and recognition that caregivers are not a homogeneous group. There is a wide range of diversity among caregivers, caregiving relationships and the circumstances within which caregiving takes place (Eley, 2003). Similarly, Toseland, Haigler and Monahan (2011) suggest that caregiver education and support programmes that include family, friends, and family issues would better address the needs of informal caregivers. Schulz et al. (2012) have also identified a lack of choice in caregivers' lives and call for interventions that take into account caregivers' values and preferences.

Conclusion

In trying to improve the outcomes for informal caregivers, a plethora of literature has explored the many permutations of informal caregiving. As this chapter has demonstrated, we know a great deal about the characteristics of caregivers; the different contexts for and the effects of giving care; but somewhat less about the efficacy of supportive interventions for caregivers. Researchers have investigated different variables in many different contexts (Purkis & Ceci, 2014). Yet, despite more than four decades of research about informal caregiving, caregivers' troubles today are strikingly similar to those of several decades ago. The same issues that were of concern in the early days of the research to a large extent remain today as informal caregivers for older people continue to experience poor physical, psychological, psychosocial, social, and financial health.

Having completed the literature review I was struck by the thought that the more the informal caregiving literature expanded the more things appeared to stay the same. In the words of C Wright Mills (2000) I felt that researchers concerned for the wellbeing of informal caregivers need to "think ourselves away" from caregiving and look at it anew.

To do this I chose the Capability Approach (Nussbaum, 2000; Sen, 1980) for my theoretical framework. I was excited by the possibilities of considering informal care in terms of what caregivers could actually be and do. In particular I liked the emphasis on the individual, or caregiver, as a worthwhile human in their own right, not simply a caregiving resource, which is how informal caregivers are so often framed in the research about them. At this point my concern for informal caregivers' health began to evolve into a bigger issue about morality and social justice. During the course of my research, Venkatapuram (2011, 2013) published his theory of health which provided a more focused approach for considering caregivers' health and wellbeing. It offers a more holistic conception of health that encompasses the social, psychological and physical aspects of health, which is important for understanding the health needs of informal caregivers for older people. Guberman (as cited in Balducci et al., 2008) has called for a paradigm shift in the way that caregiver assessment is both conceptualised and conducted, in order to provide a "new lens" through which to view caregivers' needs and circumstances. In the following chapter I introduce Venkatapuram's Theory of Health (2013) and the Capability Approach (CA; Nussbaum, 2000; Sen, 1980) as offering just such a lens.

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Link Between Chapters Three and Four

Having reviewed the informal caregiving literature, it became apparent to me that my approach to the thesis has its roots in the research concerned with the burden of caregiving. At the same time, the ethic of care literature is a close epistemological fit with my previous work around caregiving and terminal illness and my own experience as an informal caregiver. However, the Capability Approach (CA; e.g. Nussbaum, 2000; Sen, 1980) provides a useful theoretical framework for understanding informal caregivers' everyday health needs, from their perspective, in the particular context of providing care for older people.

There are many similarities between an ethic of care and the CA. For example, both are concerned with issues of gender inequality and indeed feminist writers have readily embraced the CA. For example, in 2003 the ninth issue of *Feminist Economics* was dedicated to articles on the topic of the CA. Both the CA and ethic of care studies consider the importance of social context, and are underpinned by a relational ontology, but my interest in the CA also lay in its potential to be applied to the everyday lives of informal caregivers by asking the very simple question: what are they able to do and be? The writings of care ethicists have made a substantial and valuable contribution to the field of informal caregiving research. However, the CA shows promise as a novel approach, with a pragmatic focus, that might yield fresh insights that could be used to help improve the health and wellbeing of caregivers. In this sense, the following research is concerned not only with the experiences of informal caregivers, but also with testing a new theoretical framework that will help to progress understanding of the practical aspects of caregiving and the social identity of caregivers.

Chapter Four: The Capability Approach

When health is properly understood as achieving vital goals, and the moral entitlements to the capabilities to achieve these vital goals are duly recognized as basic political principles grounded in freedom and equal dignity, the health of citizens becomes the first priority of social justice, and one of the most basic values of society.

Sridhar Venkatapuram

Introduction

In the preceding chapters concepts of care, the context for informal caregiving, and the equivocal literature regarding the impacts of providing informal care for older people have been discussed. In this final introductory chapter the Capability Approach will be outlined and discussed in terms of providing a different perspective through which to study the health and wellbeing of informal caregivers for older people.

Conceptualising health

Health may be conceptualised as “a person’s ability to achieve or exercise a cluster of basic human activities or capabilities” (Venkatapuram, 2013, p. 272). This definition modifies Nordenfelt’s (1995) theory of health, which states that health can be measured in terms of a person’s ability to achieve vital goals. Venkatapuram has expanded upon the earlier theory by explicitly naming ten central human capabilities as the vital goals left unspecified by Nordenfelt. This positive notion of health aligns with the WHO (1946) definition, which has not altered in almost 70 years, and declares that “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. This contrasts with Boorse’s (1975) definition of health that postulates health as

being the absence of disease. According to Venkatapuram, Boorse's definition is implicit in contemporary medicine and thus underpins an overriding public health emphasis on controlling or containing disease. In contrast, Venkatapuram (2013, p. 272) argues that health not only relates to the absence of disease, but it is also connected to "how they [people] feel and what they are able to do".

What people feel and what they are able to do may be explained in terms of their capabilities and functionings. This forms the basis of the Capability Approach (CA), which emerged from welfare economics and political philosophy (e.g. Nussbaum, 2000; Sen, 1980). The capabilities, referred to by Venkatapuram, in expanding Nordenfelt's (1995) definition of health, are actually a cluster of ten fundamental human entitlements identified by Nussbaum (2000; 2007, see Appendix A). Developed through a process of abstract, ethical reasoning, Nussbaum views these entitlements as constituting a minimal conception of what a dignified human life would look like in the modern world. These capabilities include:

- 1) being able to live a normal length of lifespan; 2) having good health; 3) maintaining bodily integrity; 4) being able to use senses, imagination, and thought; 5) having emotions and emotional attachments; 6) possessing practical reason to form a conception of the good; 7) having social affiliations that are meaningful and respectful; 8) expressing concern for other species; 9) being able to play; and 10) having control over one's material and political environment (Nussbaum, 2000, pp. 78–80).

Venkatapuram understands these ten capabilities as forming a meta-capability, which is the basis for health. In order to provide the context for his theory, the rest of the chapter will outline the CA, and the concepts that underpin his theory of health.

Background to the Capability Approach (CA)

The CA is a theoretical framework that draws attention to the moral importance of having the freedom to achieve well-being (see Nussbaum, 2000; Sen, 1980). This is explained in terms of people's capabilities; that is, their real opportunities to do and be what they have reason to value. Amartya Sen and Martha Nussbaum are generally recognised as the key figures associated with the Capability Approach. Sen's contributions come from a philosophy and economics background, which informs his interest in capability as an evaluative tool; whereas Nussbaum's interest in capability derives from political and moral philosophy, which is evident in her commitment to formulating basic constitutional principles. Gasper (2014) highlights this distinction and suggests that Nussbaum's version of capability would be more aptly viewed as a Capabilities Approach. Sen (1980) introduced the concept of capability because he felt that traditional economic measures failed to capture important issues of human diversity and distributional inequality. The CA provides a way of conceptualising individual disadvantage as a consequence of social, economic and environmental barriers to equality (Burchardt, 2004). It is a framework, rather than a precise theory of well-being (Robeyns 2005), hence the name Capability Approach rather than Capability Theory. The CA is now not only part of the standard curriculum in welfare economics, but also in development studies, political philosophy, education, public health and disability and gender studies, and has been incorporated into the literature on autonomy and choice, gender inequalities and power differentials (Robeyns, 2006). It has been used to measure wellbeing (Martinetti, 2000), inequality (Burchardt & Vizard, 2007) and standard of living (Breheny et al., in press); used to create new statistics and social indicators (see Anand, Hunter & Smith, 2005; Burchardt, 2004; Coast et al., 2008); and forms the basis for the

United Nations Development Programme human development index (see Fukuda-Parr, 2003).

Capability is a concept that originates from the writings of philosophers and economic theorists, such as Aristotle, Karl Marx and Adam Smith (see Nussbaum 2000, 2007, 2011; Sen, 1993, 1999). Nussbaum's version of capability, which she states began independently of Sen's work, evolved from Aristotle's ideas of human functioning and Marx's use of them (Nussbaum, 2000). In *Women and Human Development*, Nussbaum outlines the ways in which her approach differs from Sen's, both in emphasising its philosophical underpinnings and her commitment to choosing the central capabilities that she believes should be the "foundation for basic political principles that should underwrite constitutional guarantees" (2000, p.70).

In order to illustrate the ideas behind the CA, examples of informal caregiving will be used throughout this chapter. For instance, in the context of informal care, evaluating wellbeing from the more traditional income or commodities perspective would find two people with identical incomes equally well off. However, if one of those people is the informal caregiver for an older person they may be disadvantaged because of the extra costs associated with providing care. Preparing special meals, transportation to medical appointments, extra heating and laundry costs all may financially impact informal caregivers' ability to do other things they would normally like to do. In this way the financial cost of caregiving restricts the caregiver's opportunities in comparison to a non-caregiver in similar financial circumstances. Using the CA to provide richer detail about the caregivers' circumstances thus reveals a different picture (of disadvantage) from that normally revealed via a traditional economic assessment. In this way, the CA, which can be used to evaluate

both standard of living and quality of life, is concerned with people's ability to live well across all spheres of life and considers both material and mental aspects of wellbeing, or human development.

Choosing capabilities

Another contentious question for Sen and Nussbaum relates to whether or not there should be a universal list of capabilities. Sen has resisted the creation of a fixed list, arguing that the capabilities included on any list should be context specific value judgements arising from democratic public debate or participatory processes (Robeyns, 2003; Sen, 1980). That said, in his writings he has discussed capabilities such as 'avoiding premature mortality', 'securing adequate nutrition', 'availability of basic education', and 'opportunities for paid employment' (e.g. Sen, 1998, 1999), which implies that he considers these to be incontestable. Conversely, Nussbaum argues that the capability concept can only be a useful assessment tool if a specific set of capabilities has been defined as a baseline (Nussbaum, 2003). Therefore she has created a list of ten central human capabilities derived from ethical values that she believes should define and guide human development. The list has been developed from philosophy, religion, literature and consultation with poor and deprived people in India and the USA (Burchardt, 2004). Nussbaum readily acknowledges that the process of creating a list will be ongoing and certainly that the current form of the list may not be its final one. This is evidenced by amendments she herself has made to the list since its first inception. However, she has not fundamentally changed the original. Apart from the list however, Nussbaum's ideas about capabilities provide a comprehensive approach to thinking about ethics and human development (Gasper, 2014).

Terminology

This alternative approach to human development, quality of life and wellbeing focuses

on capabilities, which are the “substantive freedoms” a person has in leading “the kind of life he or she has reason to value” (Sen, 1999, p.87), and it has its own particular terminology. The following two terms are particularly important. *Capabilities* refer to an individual’s ‘real’ opportunity or freedom to be able to choose to do something. In this sense, taking a holiday is the end result of having the capability, or being able to choose, to have a holiday. *Functionings* is the capability term for the ‘somethings’ that are the various states and activities that a person can achieve. In the literature these are often described as ‘beings and doings’ (Robeyns, 2005). From the previous example, being able to take a holiday is a capability, whereas taking the holiday is a functioning. In the informal care situation, examples of ‘beings’ might include being able to care or having the opportunity for respite from caregiving. Examples of ‘doings’ would be providing care, doing the grocery shopping, or actually taking a break. Functionings can be good and bad depending on the context (Robeyns, 2011). In the context of informal caregiving, a government that relies on the provision of unpaid care by informal caregivers to solve the ‘problem’ of caring for older people would consider this arrangement to be good. However, as Robeyns points out, feminist-liberals would consider this to be a good arrangement only if the caregiving role was freely chosen in the context of equal opportunities and constructive support.

Capabilities are the relevant space to compare quality of life (Nussbaum, 2003). In this respect, well-being is conceptualised as having the opportunity to choose options from a valued set of capabilities and convert them into functionings. Disadvantage, or inequality, arises when those opportunities diminish or cease to exist. Relating this to informal caregiving, a primary caregiver who is providing continuous care over an extended period of time, for example to someone with Alzheimer’s disease, may find that they no longer have the opportunity to engage in the leisure activities that they formerly valued, such as taking a daily walk to maintain their health. This could be because the person being cared for cannot be left alone, the

caregiver does not have time to go for a walk, or they are simply too tired because of providing care for another. Over time, this loss of effective freedom (not having the opportunity to choose and achieve a valued functioning from their capability set) may cause stress in the caregiver's life; firstly because they have lost the opportunity to be able to exercise and secondly because not being able to exercise compromises their health and wellbeing. Taking this a step further, it could be argued that the caregivers' social arrangements have failed the caregiver by not ensuring that they have adequate support in their caregiving role, which enables them to pursue a regime of self-care.

One of the difficult conceptual issues in the CA is deciding whether to measure capabilities or functionings (Robeyns, 2005). In the case of informal caregiving it appears that the most appropriate metric would be capabilities because it is only through knowing which opportunities are actually available to caregivers that we can appreciate the complexity of caregivers' circumstances. Having undertaken such an assessment, it can be argued that someone who has restricted opportunities can be identified as disadvantaged or suffering from capability failure or deprivation. Furthermore, in the example above, it is likely that the informal caregiver values both caregiving and exercising, but has to make a choice between them. In this instance, the capability framework would perceive having to choose between a moral responsibility and protecting one's own health as evidence of a tragic choice that no individual should have to make (Nussbaum, 2000).

Freedoms

Capability is often equated with freedom, which can be confusing, especially as over time Sen has changed the way he uses both terms. In later years he has emphasised that capability should be understood as opportunity freedom, in other words, as "the real opportunity we have to accomplish what we value" (1992, p.31). Sen (1984) argues that

freedom should be measured in terms of what people can do, not what they have. In the literature this is often described as ‘capabilities as freedoms’, and refers to the presence of valuable options or alternatives to choose from. In this sense, freedom is not conceptualised as being able to achieve something through non-interference. Rather, freedom is conceptualised as a positive notion that involves people exercising individual agency in achieving valued goals, or being supported to do so, for example through social policy.

Agency freedom

Sen (1985) distinguishes between wellbeing freedom and agency freedom when he argues that the failure to address the crucial role of agency in a person’s life is a major limitation of outcome measures of wellbeing. Although agency freedom may be detrimental to a person’s wellbeing, in that they may choose to take drugs for example, Sen argues that it must be conceptualised as intrinsically important, because of the importance of an individual’s “real freedom” to choose. The reason for making this distinction is well illustrated in the case of informal caregiving. For example, a person may be exercising their own agency by deciding to give up a well-paid career in order to care for an elderly parent who needs help to remain in their own home. They may feel that this is the right thing to do, and the option they want to take. However, this may not be the best option in terms of their long-term wellbeing, especially if it leaves them worse off financially and prevents them from saving for their retirement. From a capability point of view, the underlying reasons why the caregiver chooses to relinquish work are important. Having this information highlights that the caregiver could be supported to choose to care or not to care, or having chosen to care, to do so without restrictions that may diminish their own wellbeing.

Diversity

An important feature of the CA is that it takes into account human diversity. One of

the reasons for developing the CA was the recognition that other normative approaches do not fully acknowledge diversity (Robeyns, 2005). This is one of the reasons why the CA is favourably regarded by feminist philosophers, or philosophers concerned with care and disability issues. They argue that mainstream moral and political philosophy has rendered invisible those people whose lives do not correspond to dominant ideals of able-bodied, independent, autonomous individuals (Robeyns, 2011). The CA considers human diversity in at least two ways. First, it emphasises the value of rich and complex descriptions of what people are able to do and be in order to determine their level of wellbeing. By including a wide range of dimensions to conceptualise and evaluate well-being, the approach broadens its 'informational basis' for assessments. In standard outcome assessments, women invariably end up disadvantaged in comparison to men. Adding more detailed information to the evaluation indicates that caregiving and the quality and quantity of social relations and support is implicated in this disadvantage (Robeyns 2003).

Conversion factors

Secondly, focusing on human diversity reveals the role of conversion factors in people's lives; these describe the degree to which a person has the opportunity to transform resources, such as income into functionings. Having the freedom to achieve valued functionings varies for different individuals. The ability to convert resources into functionings depends on personal, social and environmental factors (Robeyns, 2005, p.99). Personal conversion factors are internal to the person, such as metabolism, physical characteristics, or intelligence. Social conversion factors relate to society, such as public policies, social norms, and discriminatory practices. Environmental conversion factors emerge from a person's physical or built environment. In the capability literature the example of a bicycle is commonly used to illustrate how these three factors operate. For example, a bicycle (which is

a resource or opportunity for mobility) contributes to a person's mobility only to the extent that they can ride it (a personal conversion factor); the social mores, including whether it is socially acceptable to ride a bicycle (a social conversion factor); and the availability of adequate roads or cycle ways (an environmental conversion factor). Sen (1985) stresses that knowing a person's ability to convert the resources that they have into the things that they value is more important than knowing how much income they have at their disposal or how they feel about the resources they have. It is not enough to know the resources a person owns without knowing about the person and the circumstances in which they are living. Contextual factors and particularly structural inequalities are fundamental to any evaluation of informal caregivers' wellbeing.

Informal caregivers as ends not means

A key concept in the CA is that people should be treated as ends not means (Sen, 1999). In other words, people have intrinsic value as human beings, for who they are, not for what they can do. The main reason why the CA focuses on ends rather than means, is because people differ in their ability to convert means (such as income) into valuable opportunities (capabilities) or outcomes (functionings) (Sen 1992). The example given above of what two people, one a caregiver and one not, can achieve with the same income illustrates this point. This reflects Sen's background in welfare economics. Economists have traditionally evaluated wellbeing in terms of income or resources, and increasing income or resources is viewed as a way of improving wellbeing. Sen argues that this is the wrong approach. Instead, he maintains that income or resources can only be viewed as the means to an end, which is increased wellbeing. This has implications for informal caregiving in the following way. Caregiving research and social policy often treat informal caregivers as a resource, or the means to an end, in terms of providing cost-effective care in the community

and keeping the person being cared for out of expensive residential care. In this sense caregivers' health is only of concern when it threatens to jeopardise these goals (or ends). In contrast, the CA would argue that caregivers' health should be of concern because caregivers have intrinsic worth as human beings in their own right.

Trade-offs

In addition, the CA acknowledges that individuals differ with regard to the things they value doing and being. This is particularly relevant to the recognition and valuing of care (Lewis & Giullari, 2005). The CA requires that we consider the trade-offs that people make, with regard to the achievement of functionings. For example, an informal caregiver may choose to give up paid employment because they consider the needs of someone they care about to be more pressing than their own need to be employed. In a society where people are not fully supported as caregivers, this commitment to care reduces the set of capabilities informal caregivers have available. In this respect, Nussbaum (2000) argues that states have a duty to aim to deliver the social basis for all of the central human capabilities.

Adaptive preferences

The CA recognises that individuals have diverse preferences that are formed in the context of unequal conditions, which means that they are likely to be adaptive (Lewis & Guillari, 2005). For example, a pervasive societal belief exists that caregiving is women's work. According to this belief, the motivation to care is biologically driven with caregiving providing emotional and relational benefits for women, so monetary compensation is irrelevant (Folbre 1995; Folbre & Nelson 2000). In addition, much of care 'work' involves emotional and social support, or 'just being there', which has contributed to care being undervalued in the formal home support sector (Ungerson, 2000). In effect then, the caregiving role is socially embedded and women are expected to care, with little or no pay, regardless of their real

preference. It could be argued that some women can see no other alternative, and so they revise or adapt any aspirations they may have for a different kind of life, in order to be able to cope with the life they are leading. The same could also be said of men, especially those who are older and caring for their spouse to whom they may have been married for many years. In contrast, using the CA to evaluate wellbeing would acknowledge that people tend to adapt to unfavourable circumstances and therefore any self-evaluation in terms of satisfaction or happiness will likely be distorted.

Ethical Individualism

One of the criticisms of the CA is that it focuses on the individual and therefore does not take account of concepts such as relationality and interdependence (Dean, 2009). However, Sen takes the position of ethical individualism (Robeyns, 2005), only insofar as considering that analysis at a group level, even a unit as small as the family, will likely miss any existing or potential inequalities within these units. For example, deprivations particular to women and children may be overlooked by analyses that focus on the household if the distribution of income and commodities is inequitably distributed within that household. This argument has implications for informal caregiving, which is generally undertaken by women in the home, and usually without pay. This social arrangement has the potential to leave women in a less than ideal financial situation, whereby they are dependent upon the male breadwinner, or the state, for income. Moreover, older women may be penalised through not having amassed any retirement savings because they have been unable to undertake or retain paid employment. In this respect, the CA provides a useful framework for understanding the more complex and nuanced details related to informal caregiving.

Relational ontology

Although the ethical focus in the CA is on the individual, a social or relational

ontology is implicit in Sen's writing (Longshore Smith & Seward, 2009; Robeyns, 2005). This may explain why the approach has been so readily embraced by feminist researchers concerned with gender inequalities (e.g. Peter, 2003; Robeyns, 2003). However, Nussbaum has had the most to say about care, stating for example that "Any real society is a caregiving and care-receiving society, and must therefore discover ways of coping with these facts of human neediness and dependency that are compatible with the self-respect of the recipients and do not exploit the caregivers" (2003, p. 51). This statement points to the interdependent nature of caregiving, through which an individual's autonomy is connected and dependent upon mutual concern and responsibility. As Porter states, "Autonomy is more than choice and self-sufficiency. It involves accountability to others as a component of moral responsibility" (2001, p. 10). Thus, values are built from the meanings we share with others.

The role of resources

A common misconception with the CA is that it is not concerned with money or resources. However, the approach does recognise that being financially constrained limits opportunities to do or be many things. Paying informal caregivers has been suggested as a solution to mitigate some of the burden of providing care. While this 'commodification' of care would certainly help to improve informal caregivers' lives in some respects, it is a contentious issue (see Claasen, 2011). For example, allocating money to individual caregivers would enable more choice, including whether to care themselves or to buy care. However, as Claasen argues this may corrupt people's motivations to care. Moreover, money is unlikely to enable genuine choice for caregivers when they feel obligated to provide care within the bounds of a pre-existing relationship or when the person being cared for refuses outside help.

Lewis (2007) also argues that care work is undervalued and if commodified it is

likely to be poorly compensated financially. This appears to be the case in New Zealand, given that informal caregivers may apply for a supported living benefit to support their caregiving role. This is means tested, requiring informal caregivers to prove their 'need' and has the attached stigma of welfare dependence. The amount allocated does not enable full economic autonomy or a sense of self-worth. Using Grimmond's (2014) figures, the caregivers wage amounts to slightly more per hour than the minimum wage, and around three-quarters of the median hourly rate for New Zealanders. Lewis argues that informal carers should have genuine choice in deciding whether or not to engage in paid employment or unpaid care/work, which can only happen when men and women share caregiving tasks equally; when working time can be reduced without penalty and caregiving time fully compensated; when money is allocated to buy care and benefits for carers; and when carers have access to affordable, high-quality services. Until that happens, Lewis argues that the welfare of women in particular remains under threat right through to older age.

What the CA can add to informal care research

In many ways the concepts underpinning capability are similar to an ethic of care. Both recognise the importance of social context to specific situations. The capability literature similarly recognises the importance of caring for others (Nussbaum, 2000, 2003; Sen, 1985, 1999). This is conveyed through the notion of *ubuntu*, a Bantu word, meaning that you only become human through your relationship with others (Alkire & Deneulin, 2009), which resonates with the relational ontology implicit in the ethic of care literature, through its emphasis on the giving and receiving of care. Of the capability theorists, Nussbaum in particular focuses on care, stating that the CA "provides the best framework within which both to value care and to give it the necessary critical scrutiny" (2000, p.244). She recognises the health sacrifices women make when, as unpaid caregivers they put others' needs before their own. Nussbaum argues that this raises injustice issues, noting that "people love best when they

are in other respects flourishing, not when they are exhausted, or struggling to make ends meet” (2000, p.297).

In psychology, flourishing means “to live within an optimal range of human functioning, one that connotes goodness, generativity, growth, and resilience” (Fredrickson & Losada, 2005, p.678). This definition of flourishing echoes Venkatapuram’s (2011) view of health as a positive state rather than as a state characterised by absence or lack. This notion of health as opportunities to achieve vital goals, in conjunction with the concepts underpinning the capability framework has the potential to contribute to the care ethics literature by providing a new lens through which to view, conceptualise, and evaluate informal caregivers’ health needs.

The thesis aim

This research has one overarching objective, to explore the health needs of informal caregivers. This is achieved by asking two research questions. The first research question relates to Study One. The second research question relates to Study Two and was generated from the findings of the first study.

Aim One: To explore the health needs of informal caregivers.

Research Question One: Which capabilities are important for informal caregivers’ health and wellbeing?

Research Question Two: What role do emotions play in the everyday lives of informal caregivers for older people?

The study also has an ancillary aim.

Aim Two: To use the capability approach to frame the research

Research question: Can the Capability Approach be used as a theoretical framework to understand informal caregiving for older people from a new perspective?

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About the Author

Psychology needs to concern itself with life as it is lived...

Gordon Allport

While writing this this thesis I have worn many hats. Researcher, student, public health surveyor, informal caregiver, daughter, mother, first-time grandmother, best friend and wife. All of these roles are intertwined and have contributed in some way to this document. However, the role of informal caregiver in particular is integral to the study.

The foundation for this research was laid in 2002 when my father was diagnosed with cancer. Although I was not his primary caregiver, as the only daughter and only family member living in close proximity to my parents I was the main support person for them both. My mother did not drive and had always relied heavily on others, especially my father, to do things for her. I was therefore in a good position to observe how the system worked (or did not work) to support people who were dying and their caregivers.

Following Dad's death in 2004, I completed my BA, having begun my studies 3 years prior as a mature student. The following year, I took the opportunity to continue my studies at Masters level; choosing end-of-life care for older people in a rural community as my thesis topic. I was also working as an administrator organising home support for older people and people with disabilities which enabled them to continue living in the community. These experiences fuelled my interest in caregiving and particularly the health and wellbeing of informal caregivers. When the opportunity arose, I chose to pursue this further, as a PhD student. At the same time, my mother's health was deteriorating and my

role as daughter gradually evolved into the role of primary caregiver.

This role continued throughout the course of my research, and was particularly demanding during the data collection and analysis phases. Did my experience as a caregiver colour my role as a researcher? Of course! Did the participants' experiences affect my perception of caregiving? Absolutely! My caregiving experiences fostered an empathic rapport with the participants, especially during the second phase of data collection, as well as providing additional insight into the data collected. On the other hand, the participants' experiences helped me make sense of my own caregiving trajectory as well as suggesting ways in which caregivers could be better supported. Additionally, in my other life, outside of caregiving and being a PhD student, I constantly came into contact with people who were experiencing what I was writing about; both as caregivers and as people being cared for. My informal conversations with them and observations of their lives cannot help but have had an indirect influence upon my reflections as a researcher.

Towards the end of the study, my research life was placed on hold as I prioritised care for Mum during her final weeks. Again, I reflected on the all-consuming commitment associated with my experience as a primary caregiver and daughter and what I had learned from the study participants. I was able to look back to where I had started, when the study topic was first conceived and a theoretical framework was chosen, and reflect upon the progression of my thinking as well as my expectations for myself as a caregiver and person. This thesis is situated against that experiential background and made possible by collaboration with all of the caregivers who so generously participated in the study, enabling the construction of the following work.

I choose the word construction deliberately. It refers both to the epistemological assumptions of social construction as well as the process of putting the thesis together. The

latter is reflected in the way I have chosen to present my work as a series of papers cemented together with explanatory comments that reflect my thinking about what has gone before and the rationale for what will happen next.

In order to address the challenges of structuring a thesis by manuscript or published journal articles, linking sections have been added to improve the flow and elaborate on details that have been omitted or condensed due to word constraints required from a journal article. Additionally, it should be noted that presenting the empirical and theoretical background in each article has meant some content has been repeated. The next three chapters, Five, Six, and Seven comprise three manuscripts relating to Study One.

Link between Chapter Four and Chapter Five

Chapter Five describes the methodology for this study, as well as discussing the challenges and successes encountered in using an online forum as a method for data collection.

A participatory methodology was chosen for the first study for two reasons. Participatory principles sat well with my own research values and dovetailed neatly with Sen's (2004) belief in deliberative democracy. The online forum was designed so that participants could join quickly and easily. They did this by clicking on a hyper-link contained within a website they had visited or by accessing the dedicated *carersvoices* website, having read about it in a carers' magazine or newsletter. The participants did not have to contact me, as the moderator, to be vetted or given a password enabling access. The reasons for this set up were two fold. Firstly, the caregiving literature had highlighted the time constraints in caregivers' lives and I thought by giving them easy, spontaneous access it may be more likely that they would participate in the forum, rather than thinking "I will do this later when I have more time" or just finding the whole process too onerous.

Secondly, I had decided not to collect demographic data and therefore I did not require the participants to provide these details. There were several reasons for not collecting demographic data. This was an exploratory study concerned with the health needs of informal caregivers for older people in general, therefore I was not looking to analyse the data by ethnicity, age, socio-economic status or location. Secondly, and this relates to the previous comment about the busy lives of caregivers, I wanted the participants to have instant access into the forum discussion. Finally, I asked the participants not to provide demographic details in the forum itself so as to help preserve their anonymity.

Despite my best intentions, the online forum did not produce the cohesive, invested group of caregivers that I had, perhaps naively, imagined at the outset. Instead of coming together to interactively discuss and debate their issues via the forum, which I had anticipated would be followed up with co-analysis of the data to form the basis of a capability list specific to informal caregiving for older people, the participants took advantage of the forum to tell their individual stories. They came, they narrated their experiences, and they mostly left. In this sense, the forum offered a space where they felt comfortable to tell their stories, providing a considerable amount of rich data that formed the basis for the following three papers and suggested a new, albeit unanticipated direction for a second study. This experience taught me to expect the unexpected and the value of flexibility when working with others, especially when participatory principles are important.

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Chapter Five: Study One - Method

Horrell, B., Stephens, C., & Breheny, M. (2015). Online research with informal caregivers: Opportunities and challenges. *Qualitative Research in Psychology*, *12*(3), 258-271.

Abstract

In this paper we discuss the opportunities and challenges of using the Internet as part of an emergent methodology in qualitative research. Utilising a deliberative process of democratic enquiry, an online forum was used to identify important capabilities for the health of informal caregivers for older people in New Zealand. Recognising the difficulties associated with recruiting and interviewing informal caregivers, the study was advertised and conducted via the Internet. Over four months, 60 informal caregivers, from varied backgrounds, contributed to an online forum created specifically for the research. The asynchronous, anonymous format facilitated participants' personal accounts of caregiving which highlighted the tensions and complexity of caregivers' lives. This resulted in a key finding that emotions, and particularly attachment, play a significant role in the day-to-day experience of informal eldercare provision. Overall, we found that Internet-mediated research offers an innovative option for qualitative data collection, which has potential for including hard-to-reach populations, and enabling insightful, contextual data collection.

Online research with informal caregivers: opportunities and challenges.

Introduction

Internet-mediated research (IMR) is an emergent research method, which is proving to be valuable in the social and behavioural sciences (Hewson, 2008). Adapting traditional qualitative methods such as interviews, focus groups and ethnography into an online format has created innovative options for gathering research data (Hine, 2008). Denissen et al. (2010) predict that web-based research will continue to proliferate as more people embrace the Internet and more advanced, user-friendly technologies develop.

IMR has many advantages. It is a cost and time efficient alternative to traditional methods that is convenient for participants (Hewson, 2008). The anonymity afforded by online interaction can positively affect communication (Denissen et al., 2010) and may increase candid disclosure of thoughts and feelings (Valkenburg & Peter, 2009), especially with regard to sensitive topics (Moynan, 2013). The Internet provides access to a large, and diverse population of Internet users (Hewson, 2008), giving researchers the opportunity to access and recruit particular populations (Hesse-Biber & Griffin, 2013), or communities and networks with shared interests, such as political activists (Biddix & Park, 2008). Although some populations will be inevitably excluded due to a lack of computer literacy or access, Gosling et al. (2004) found that Internet samples can be more diverse than traditional samples. Because the Internet has potential for including participants who might normally be considered difficult to reach (Levine et al., 2011), IMR opens up possibilities to involve marginalized, socially and geographically isolated populations in research, as well as people who are ill, disabled, or housebound, and those who would find it difficult to participate in offline research because of time constraints (Tates, 2009).

Being able to reach wider and more diverse populations via the Internet offers new possibilities for democratic participation (Smith et al., 2013) by providing public fora that foster inclusivity. As well as providing a means to reach and involve geographically dispersed contributors, the Internet offers an engaging form of participation in a protected, or anonymous, environment (McGrath et al., 2012). Macintosh (2004, p. 2) provides an analytic framework for using Internet technologies such as electronic participation to improve democratic processes. The goals of 'e-participation' are to: reach a wide-ranging audience to enable greater public participation and influence decision-making; support participation through technologies suited to different levels of technical and communicative skill; provide relevant, accessible information; and enable meaningful contributions that can be analysed and disseminated to maintain openness and transparency. Likewise, Sæbø (2008, p. 400) notes that "e-Participation" may potentially transform people's involvement in public deliberation and decision-making. Asynchronous online discussion forums provide a particular example of deliberative e-participation that enables informed discussion between participants about a common concern that leads to collective decision-making (Wright & Street, 2007). While this type of e-participation is most commonly used as a 'top-down' process for public consultation, the capacity for an Internet forum to engage a large number of participants from diverse backgrounds in a public decision-making process (Margolis & Moreño-Riano, 2009) was a defining characteristic that determined the use of this approach as a research method in our study of informal caregivers' health.

Informal caregivers are mostly unpaid family, friends and neighbours of a care recipient who depends upon help with activities of daily living. The largest caregiving group provides eldercare; adult children (mainly daughters) caring for parents are closely followed by elderly women, caring for a spouse or partner (Schofield et al., 1997; Wolff & Kasper,

2006). Caregiving research documents the burden associated with informal caregiving and the resulting negative effect on caregivers' health (e.g. Pinqart & Sorensen, 2003, 2007; Zarit, Reever and Bach-Peterson, 1980), as well as the positive aspects of caregiving (Kinney & Stephens, 1989; van Durme et al., 2012). Alternatively, positive and negative experiences may co-exist (Toljamo, Perälä, & Laukkala, 2012), often manifesting as ambivalence towards the provision of care (Shim, Barroso & Davis, 2012). The apparent contradictions in findings are generally attributed to methodological differences in study design, the diverse contexts for care, and the measurement of different dimensions of caregiving (Brown & Brown, 2014; Van Groenou, de Boer and Iedema (2013). Overall, informal caregiving research has produced inconsistent findings. Internet methodologies provide an opportunity to increase access to caregivers' voices, adding a more nuanced and contextual dimension to the discussion of the experience of informal caregiving.

For research purposes, informal caregivers may be understood as a difficult to reach population (Fredriksen-Goldberg & Hooyman, 2007). There are several reasons for this. Firstly, family members, and particularly spouses, tend not to self-identify as informal caregivers (Dobrof & Ebenstein, 2003). Consequently, they are unlikely to respond to invitations to take part in research about informal caregiving. Second, caregiving responsibilities affect informal caregivers' control over their daily lives (Barrett, Hale, & Butler, 2014). Unceasing availability to a care recipient restricts informal caregivers' mobility and limits their ability to commit to activities outside the home, thus making it difficult to engage in research away from home. Additionally, time demands and the unpredictable nature of providing care may make it difficult to accommodate the intrusion of interviewers whilst providing care at home. Utilising the Internet as a vehicle for informal caregiving research removes some of the barriers to participation, and thereby broadens

access to caregivers' voices in research about care provision. To this end, we aimed to provide an accessible online forum where geographically dispersed caregivers could join together as a community of interest to discuss their experience of providing informal care for older people. The goal of our research with caregivers was to understand the values and health needs of those providing informal eldercare. In this paper we provide an outline of the methods used to engage a wide range of caregivers for older people in a deliberative process that involved them in developing this knowledge, and we discuss the challenges and successes encountered in using this approach.

An Asynchronous Online Forum.

Method

The theoretical framework for the study was Sen's (1980) Capability Approach (CA) which explores wellbeing in terms of having the capability to achieve valued activities. Sen (2004) argues that any list of essential capabilities is context-specific, and should be decided through a democratic decision-making process. Sen's (2004) focus on identifying capabilities through deliberative democracy was a fundamental principle underpinning our decision to create the online forum, *carersvoicesnz*. Via the forum, we aimed to engage informal caregivers for older people in dialogue to generate knowledge grounded in their experience. Participatory principles informed our study design, by acknowledging that people are experts by experience (Nind et al., 2013) and promoting research with, rather than on, participants. This contrasts with 'top-down' deliberative research that encourages deliberation based on the views of the researcher, or external experts (Burchardt, 2012). In this sense, the study design incorporated a mix of both deliberative and participatory aims. It provided the opportunity for caregivers to deliberate together, about the kinds of things *they* valued, in terms of keeping themselves healthy. This enabled the development of a list of common,

valued capabilities that is specific to the context of informal care provision for older people and has practical implications for future service provision aimed at improving informal caregivers' health. These aims were stated in recruitment material and on the website's Home Page.

Creating the website

The first author created the website that hosted the forum, as well as maintaining and moderating the forum. The website contained a Home Page, which provided a brief overview of the study and tabs for other web pages: Information Sheet; Privacy; Netiquette; Me (information about the moderator); and a Contact Me tab with the moderator's contact details.

The Information Sheet provided details about the research project and described what would happen to the data from the forum, which is an often debated issue for IMR (Denissen et al., 2010). This included data storage while the forum was live and dissemination of results. A summary of results was posted to the home page of the website and remained accessible until the website was taken down several months after the end of the forum. The Privacy page, subtitled "Keeping yourself safe online", described security measures including asking participants to use a pseudonym; a statement reassuring the participants that their details would not be passed on to any third parties; and assurance that they would not be susceptible to junk mail or spam as a result of using the site. The Privacy page also discussed the public nature of the forum with a caution not to contribute anything that could identify themselves or the person receiving care. A link on the page directed participants to a list of potentially useful websites, should they require support for any issues raised in the forum, or

support for caregiving in general. The Netiquette page provided guidelines for Internet etiquette to clarify expectations regarding Internet discussion board posting.

The Forum tab led to the discussion board, and included a page that provided detailed instructions about how to post a comment. This was designed to assist participants who were unfamiliar with using online forums. The forum was planned to run as a series of discussion boards over four weeks. A discussion board entails posting a set of questions on a website that can be responded to at a later time by participants (Strickland et al., 2003). In this case, the moderator posted a series of theory driven topics, informed by the caregiving literature and framed to reflect the capability concepts of opportunity, freedom, and agency (see Deneulin & Shahani, 2009). The prompts were posted as a discussion thread to which participants could respond. Alternatively, they were able to begin their own thread. In effect, *carersvoicesnz* became a series of four forums. In forum one, the participants described how and why they became caregivers. Forum two focused on self-care. In forum three, the participants discussed their experience of the caregiving process over time. In forum four, participants introduced their own topics for discussion. The open format of the forum accorded the participants equal opportunity to contribute anonymously and facilitated the emergence of topics driven by the caregivers' own experiences. At the end of four months, the forum expired. All of the forum information was downloaded by the hosting service and the webpage was erased from the website. A subsequent Google search of entire phrases from the forum yielded no result.

The decision to create a website specifically for this research was based on a concern to protect the privacy of the participants, as it was more likely that visitors to the website would be only interested in the topic of informal caregivers' health. Alternatively, an existing service such as Yahoo, Facebook or Twitter could have been used to host the forum. These

services send notifications of new postings which may have increased interaction, however, receiving an alert every time someone posted to the forum was considered potentially intrusive.

Recruitment

Research consistently describes informal caregivers as overburdened and socially isolated (e.g. Barrett et al., 2014; Legg et al., 2013), which suggests that they may be reluctant to participate in research. Because the Internet has been identified as an effective means of accessing hard-to-reach populations, we utilised the Internet for recruitment. Organisations associated with eldercare promoted the study on their websites. These organisations displayed an article about the research, which contained a hyperlink to the *carervoicesnz* website, in their magazines, newsletters, on their own websites and Facebook pages. Interested caregivers could access the website with one mouse click, which enabled easy, instant access.

Many people are unlikely to self-identify as ‘informal caregivers’ when supporting someone with age-related disabilities (Dobroff & Ebenstein, 2003; Walker, 1995). To include a wider group, we also advertised on a website for people over 50 years, and an online auction website with a substantial membership and community message board, to reach younger caregivers. The online auction site was a very useful method of recruitment and data collection. Considerable media interest in the study provided additional promotion. The recruitment method could be considered an online version of snowball sampling (Sadler et al., 2010), in that support organisations and message board members acted as intermediaries to source potential participants and promote *carersvoicesnz*.

Participants

Sixty informal caregivers took part in the study. To be eligible, participants, of any age, needed to be living in New Zealand and caring for someone in the community aged 65 or older. The caregivers were asked to use pseudonyms and not to provide demographic details, to protect their anonymity. However, contextual background details from the participants' postings indicated that the participants' ages ranged from late teens through to mid-sixties, with only two participants identifying as male. The participants included spouses, daughters, a son, a granddaughter, and non-kin caregivers; they provided care for people with various illnesses associated with ageing including, Alzheimer's disease, Parkinson's disease, heart disease and cancer. Some of the care recipients had co-morbidities, and several of the caregivers were caring for more than one person.

The first author assumed the role of forum moderator and attended to any technical problems on the website. In the first week she posted to the forum to introduce herself and to describe her personal experience of providing informal eldercare to establish common ground with the participants. By focusing primarily on being a fellow caregiver, in preference to an academic researcher, the moderator aimed to encourage less confident participants to contribute (Williams et al., 2012). The moderator initiated prompts in the form of 'discussion threads' to stimulate discussion in the first three forums, and moderate threads created by participants. Overall, the moderator aimed to facilitate interactive reflexivity in a 'safe' environment while limiting her contributions to clarification or asking for further information. This flexibility was a critical aspect of the forum.

Finding the 'right' balance between building a rapport with the participants without dominating the discussion was difficult to manage, due to the lack of immediate feedback,

such as body language cues, that would be available in a face-to-face environment (Moloney et al., 2003). In this study, the participants controlled the extent of their contribution. At times they ignored the moderator's questions, choosing to focus on what interested them, as opposed to what the researcher asked. Choosing not to respond may be peculiar to asynchronous online discussions, as it would be very difficult to completely ignore an interviewer's question in a face-to-face situation. In this respect, compared to traditional interview methods, the online context enables the participants to resist the researcher's framing of the research and consequently shifts the power relations between the researcher and the participants, which may be considered a benefit of IMR.

Ethical considerations

Much of the debate regarding ethical issues in online research focuses on the public/private distinction, and downloading data without consent, especially for the analysis of naturally occurring data. In this study, the participants knew that their contributions to the forum were being used for research. The study was designed for ease of access; the participants did not have to contact the forum moderator for a password. Every webpage contained a link to the Information Sheet. The participants were invited to read and understand the Information Sheet before entering the Forum. Therefore, the forum moderator assumed participants followed these instructions, and met the criteria for informed consent. The study was approved by the University Human Ethics Committee.

A key reason for designing the Internet forum was to bring together participants from a nationwide catchment, enabling participants to join the forum who might otherwise have been unable to take part due to their location or caregiving commitments. In the following section we focus on some particular issues around the aim to represent a wide range of caregivers' views from across New Zealand.

Challenges and Successes

Technical issues

Some people experienced technical difficulties with participating. In the forum there were several instances in which postings were duplicated, or nothing appeared at all after a posting had been started by entering a title and pseudonym. Participants occasionally commented about difficulties accessing the forum, “*I have popped back in!! However it was with some difficulty because as my Grand-kids say... I am technology challenged!*” (Sarah, female caregiver for her father and spouse). These difficulties may be compounded among older people. While older people are increasingly using an online environment to search for information on the Internet or send emails (Fausset et al., 2013; Leist, 2013), they may struggle with operational and formal skills (Van Deursen and Van Dijk, 2011). Although problems of this nature may be specific to this participant group, the majority of whom were older; they do highlight the design requirements to provide clear, detailed instructions from the outset, as well as a moderator, as provided in this study, to resolve technical problems while the forum is in progress.

Forum interactions

The ways in which members in an online community respond contributes to its health or success (Angeletou, Rowe & Alani, 2011). Too much of any type of responding will influence how others act and may cause people to withdraw from the discussion altogether. Although this is a relatively new field of research, certain ways of responding have been identified, such as ‘supporters’ who form the backbone of the community and ‘grunts’ who contribute very little (Chan, Hayes & Daly, 2011). Moderators also have a role in managing the community, especially to moderate inflammatory or disruptive behaviour such as ‘flaming’ or ‘ranting’. There was no evidence of this kind of behaviour in the *carersvoicesnz*

forum, which may be attributable to being a research specific community. The issues we noted were in regard to the nature of forum interaction owing to the timing of exchanges and a tendency to post monologues.

Sporadic participation

Participation in the forum was sporadic. There were two main periods of activity, both of which coincided with promotion of the study. The first occurred when the study was first advertised on the support organisations' websites, and tapered off after the first two months. A second flurry occurred approximately one month later in response to media promotion. Initially the forum worked to facilitate interactive discussion, as intended. However, towards the later stages, the postings were mostly personal monologues that elicited supportive affirmations rather than discussion. The extended, asynchronous nature of the forum may have contributed to this. This was a deliberate feature of the forum which recognised the time demands and unpredictable nature of caregiving and allowed participants to come and go as it suited them, rather than requiring them to log on at a particular time. However, the asynchronous nature of communication also meant that participants did not receive immediate responses, as they would in a chat room or a face-to-face focus group, and this limited interactions.

Monologue posting

Contrary to our expectations monologue postings predominated throughout the four forums. We had anticipated that as a sense of community evolved, based on informal caregivers' common interest and personal experience, the research forum would facilitate deliberative interaction between the participants as they discussed the things they valued for keeping themselves healthy. While several participants posted repeatedly and responded to previous postings, others responded once to a posting and then took no further part in the

discussion. Additionally, at times there was no response to prompts from the moderator, suggesting that participants posted their comments and did not check back. Contributing an opinion but leaving without interacting with others is called monologue posting, and is a common criticism of online forums (Jensen, 2003). However, in this study monologues contributed important contextual detail. This may have been due to the social context of an asynchronous online forum, which is advantageous for the disclosure of personal information. It allows participants time to read and digest messages, and consider their own responses before replying. This produces reflexive accounts of participants' lived experiences (Williams et al., 2012). In this study, the participants' insightful monologues provide a valuable complement to what is already known about caring informally for older people. This challenged our preconceptions of what we expected the forum could offer, as we came to realise that the number of messages posted, or the amount of interaction in an online discussion is not necessarily a measure of its success. Rather, the content of the postings is equally important, especially in a research environment.

Established and research focussed communities.

Promoting the study on the online auction website provided a serendipitous comparison and valuable information about responding in a public forum. While the online community message board provided a direct link to the website and some community members joined the research forum via the link, others started chatting on the auction site. Despite the forum moderator's invitation to take their discussions into *carersvoicesnz*, the community message board thread continued. Compared to the research forum there were more interactive postings on the community message board in a shorter time frame perhaps indicating a preference for spontaneous, synchronous interaction in that particular environment. As in *carersvoicesnz*, certain contributors were more visible, taking the

initiative to ‘bump’ the thread to bring it back into view if it went quiet. The online auction site had an established sense of community, with participants mentioning that they had ‘met’ in previous threads, which may have contributed to their readiness to take part. The community members all used pseudonyms that they had chosen for that website and were therefore easily recognisable to each other. This suggests that an established online community could facilitate communication among those who already use the Internet for information and support, rather than setting up an online community specifically for research purposes. On the other hand, a specifically developed site may encourage participation from those outside an established online community and so encourage a wider range of views.

Mutual support

Those who did respond to each other used conversational reciprocity which indicates “real discussion” (Janssen & Kies, 2005, p.13). These interactions were often supportive, *Thank-you for sharing. I read your experience and I found your devotion to your husband very moving* (Dee, female caregiver for her mother). Other comments were appreciative, especially in regard to helpful formation, *Thanks Pam for your comments as I am alone in this situation and aren't aware of who to turn to for help.* (Margie, female caregiver, caring for her mother). In this forum, reciprocity included affirmation, empathy, support and gratitude for a posting, which Barak et al. (2008) suggest is typical of a group that comes together to discuss a particular issue. These affirming posts often generated further disclosure which revealed valued capabilities. For example, Sarah responded to Kath’s long posting about her husband’s transition into residential care with the following comment, *“Thank-you Kath for having the courage to share. You have done a great job and made the right decisions for your husband and for yourself”*. She then responded with her own story about

her father's transition into residential care and coping with her husband's increasing dependency.

Lurkers

There may have been people in the forum that just observed or 'lurked'; that is, they read the posts, but did not join in. Janssen and Kies (2005) suggest that people who lurk are important to the deliberative process. They argue that researchers interested in deliberative democracy should capture this information, because participants are gathering information by reading other's contributions and deliberating on the content may influence or change their own thoughts. The impact of the research on those not participating could have been considered at the design stage and accommodated through a more sophisticated hosting service that provides site traffic information.

Methodological influences on the findings

The resulting data was initially analysed to meet the aim of developing a common list of valued capabilities. The rich data which resulted from the participants' contributions prompted a second interpretive iteration of the analysis, which utilised the concepts underpinning the Capability Approach, to delve more deeply into the data and construct an overall narrative about caregiving. This analysis was undertaken in response to the ways the participants' responded to the forum. Rather than the interactive space envisaged by the moderator in which the participants debated the importance of a range of capabilities for flourishing, the participants contributed in an asynchronous way that better suited their own needs. This type of responding produced detailed narratives of the pathways into care, tensions in the experience of caregiving, and uncertainties of the future of the caregivers. Doing justice to these detailed narratives required a new approach to the analysis of the data.

The results provide nuanced insights into the specific context of providing informal care for older people.

A key finding from this second analysis of the forum data was the significance of emotions in the caregivers' relationships with those they cared for (Horrell, Stephens & Breheny, 2014). The online study method may have enhanced the disclosure of emotional aspects of the caregivers' lives through disinhibition as described by Suler (2005). For example, Madge and O'Connor's (2002) study of 'E-Mums' noted an openness and willingness among the participants to voice their opinions, which Hesse-Biber and Griffin (2013) describe as a strength of IMR, while also noting that participating from the 'safety' of their own homes may influence the inclination to contribute. We found a similar effect in this study. For example, many participants responded to the moderator's prompts with detailed stories, providing in-depth, contextual details that contributed to an overall narrative about caregiving. The narratives ranged from spontaneous responses to another participant's story to reflexive narratives that had been composed with a great deal of thought. For example, Kath's contribution was written as a word document and pasted into the forum. She wrote in detail about caring for a husband with Alzheimer's disease and her eventual decision to move him into residential care. The posting contained many examples of her struggle to make the 'right' decision as her husband progressed through the different stages of the disease. Initially, Kath says she was happy, despite having to "*reorganise my life, and give up on few things sports, meeting with friends, as i had to continue working*". She continues by describing how she coped with caregiving until eventually:

finding time to sleep became a problem, finding time to work became a problem, shopping became a problem, the agency stopped sending their staff as they were 'afraid', i myself felt threatened a couple of times. My husband's behaviour started to

cause concerns for my safety, my family and the medical profession advised me to think about a rest home (specialized for dementia care).

Kath ended her story with the comment, “*thank you for letting me write it up this way, i felt i needed this*” (female caregiver for her husband). This forum thus provided a space for participants to describe their experiences in detail and enabled narrative depth in the data.

Benefits of Internet Mediated Research

Previous studies have noted that informal caregivers tend to provide socially desirable responses in research about themselves. For example, Pickard (2010) describes the moral narratives caregivers draw upon to justify their behaviour and choices, and present themselves as ‘good carers’. BurrIDGE, Winch and Clavarino (2007) attribute this to the contemporary cultural context for caregiving in which the expression of negative feelings towards providing informal care may be interpreted as a transgression of social norms. In her videographic study of informal caregivers, Silverman (in press) notes the tension experienced by the participants who “could not overtly resist the role of caregiver because there was no social space in which to do so...yet they could not sustain the role indefinitely”. In our study the anonymity afforded by the online format provided a social space for participants to express themselves more openly with less concern about being judged by their peers or the researcher.

This was achieved in several ways. First, participating from their homes provides a sense of safety that results in less inhibited responses and increased honesty. Second, the anonymous nature of online research facilitates the self-disclosure of detailed personal information. In the online context, participants know only what other participants tell them, which encourages the disclosure of sensitive information participants may be reluctant to

share in a face-to-face situation. Third, invisibility of the online context contributes to the sharing of less socially desirable responses. Finally, the online format works to equalise the relationship between the researcher and the participants, facilitating more candid responses. In this respect, being able to express their emotions in the research context contributed to a deeper understanding of the role that emotions play in their daily lives as caregivers.

Conclusion

We identified both advantages and challenges to using an online method for deliberative social research. The forum provided an accessible, convenient and flexible environment for a geographically dispersed, hard-to-reach population, who might otherwise have been excluded from a study utilising traditional research methodology. The asynchronous nature of the forum allowed the participants to contribute when it was convenient for them and provided time for reflection before responding, which resulted in rehearsed narrative data, particularly used to retell the events which led up to the decision to care. These advantages suggest that an asynchronous format has the potential to be more widely utilised in narrative research. Additionally, the posts were able to be downloaded in their entirety, into a word processing document, which meant transcription was not required, removing potential transcription error and expediting analysis. While participants' grammatical and spelling errors may hamper comprehension or interpretation in Internet research, this was not the case in this particular study.

In this study, features particular to online research such as anonymity, invisibility and inclusivity, combined with the asynchronous format, facilitated the disclosure of contextual, in-depth data, which provided insight into the participants' lived experiences. However, the use of Internet technologies for deliberation and research may differ according to context (see McGrath, 2008 for a critical discussion on the scope and limitations of the democratic

potential for e-participation). The digital divide is often cited as a barrier to inclusivity and we acknowledge that informal caregivers may have been excluded because of a lack of Internet access. In terms of proficiency, for those who had access, our forum design meant that participation did not require advanced skills and a moderator was on hand to attend to any technical issues as they arose. Another criticism of the Internet interaction relates to privacy risks. This was less of an issue in this study because the forum was constructed specifically for research purposes and recruitment was conducted in a way that was unlikely to attract participants who were not interested in the study aims. Finally, by incorporating participatory principles in the study design, we attempted to address the potential for any imbalance in power relations, which could be considered a shortcoming of both deliberative and Internet-mediated research. This enabled the caregivers to participate on their own terms, in a way that was comfortable for them. On balance, the use of asynchronous discussion fitted our participants' needs and the data they provided led to novel findings in the area of informal caregiving for older people and recommendations for practice (Horrell, Stephens, & Breheny, 2014). This suggests that asynchronous Internet forums may prove useful as an online version of deliberative research; a research method that Burchardt (2012) recommends as having potential in studies concerned with making value judgements aimed at informing social policy.

Internet-mediated research is an innovative, emergent area for qualitative data collection that has enormous potential, especially for including hard-to-reach populations, and is likely to be increasingly utilised in future research. Researchers will need to consider carefully the study aims, the target population, and available resources to determine whether the Internet, and which method of digital data collection, will be most suitable for their particular study. While careful planning and design, tailored to fit the study aims, is essential,

this study suggests that an eclectic, or hybrid, approach works well. Participants' spontaneous interaction in a public online space suggests the potential for utilising pre-existing forums in future online research. Internet-mediated research is likely to evolve at a rapid pace, alongside Internet usage. Therefore, innovative methods that incorporate eclecticism and flexibility to provide a democratic space for participants and researchers to interact are likely to prove desirable and necessary tools in the qualitative researcher's toolkit.

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Link between Chapter Five and Chapter Six

Chapter Six is the first results paper and discusses using the Capability Approach (CA) as a framework for analysis in Study One. I used Nussbaum's (2007) version of a capability list as a template to thematically analyse the forum participants' narratives. The complete list is included at the end of this section, as limited space precluded inclusion in its entirety in the manuscript. Using the capability list to organise the data from the forum is somewhat of a realist approach, which stands in contrast to my personal leanings towards social constructionism. As a nod to this epistemological stance, I tried to introduce, where feasible, opportunities for the co-construction of information between the participants and myself as researcher. I could have chosen a methodology similar to dynamic public reflective equilibrium used by Wolff and De Shalit (2007) in their exploration of disadvantage. In their study, they asked participants to reflect upon Nussbaum's list (albeit revised and extended by them). However, I deliberately chose a "bottom-up" approach that was much more open-ended as that was a better fit with my own research values. Via the online forum participants were prompted to interact with open-ended questions, and space was made for the participants to introduce their own topics for discussion. The first discussion began with "*The discussion this week will be about how you became a carer and why*". Once people began to contribute, I introduced more focussed questioning informed by the capability approach, but only if it had been raised in the discussion. For example, "*I found Sue's comment about having no choice very interesting. What do others think about choices they may or may not have had?*" This contrasts with the more usual approaches used in democratic deliberation whereby participants are asked to respond to and deliberate upon set questions.

Nussbaum's list was not introduced until the analysis stage, when I used it as a template to guide the thematic analysis (King, 2012). In this respect, the capabilities worked as *a priori*

themes. One of the challenges of using an *a priori* template is the temptation to force the data into the categories. This is something that I initially struggled with, seizing upon excerpts if they contained any reference to one of the capabilities in Nussbaum's list, which meant that the categorisation was somewhat superficial. As I refined the process my analysis became more interpretive, based on meaning and ensuring it was a good fit with Nussbaum's conception of that capability.

Nussbaum (2003, p.33) argues that the concept of capability can only work if there is a "definite set of capabilities" and her list of central human capabilities has been intentionally constructed at an abstract level so that it stands above the variations of daily life (Anand et al., 2009), yet she variously describes it as universally fixed and as open to modification. Therefore, it may best be understood as providing a partial rather than an exhaustive account of what constitutes a 'good life'. Being open to further specification increases the list's utility in different contexts. For example, it has been used to develop capability indicators in the field of professional education (Walker et al., 2009); in a study of migrant workers in Turkey (Uyan-Semerci, 2007); and in Wolff and De-Shalit's (2007) investigation of disadvantage.

Additionally, the CA was originally devised as a way of evaluating standard of living and quality of life in under-developed countries and I was trying to apply it to a different context, that is, caregiving in the 'developed' world. In this respect, at first glance some of the capabilities may appear irrelevant to the lives of informal caregivers in New Zealand; for example, being adequately nourished or having adequate shelter. In such instances I have extrapolated what I perceive to be the essence of the capability to the present context. As an example, having adequate shelter (which is a sub category of the second capability on Nussbaum's list) in the context of this study might mean being able to choose to own one's home as opposed to not having that choice because of changed living or financial arrangements as a result of caregiving. Expanding the list in this way with real life examples demonstrates the

‘further specification’ that Nussbaum argues is required in any capability list.

It could be argued that using Nussbaum’s capabilities as a template to categorise the caregivers’ responses appears circular (Nussbaum, 2011), in that I have found what I set out to find, and that undertaking a thematic analysis without pre-existing themes would have been an equally useful method to consider the caregivers’ contributions to the forum. However, the CA was chosen as the theoretical framework for this study because it offered an alternative approach to previous research by asking “what are informal caregivers able to do and to be?” It therefore made sense, to me, to utilise the capabilities on Nussbaum’s list as a priori themes because they related to important theoretical concepts that had informed the design and aims of the study. Conducting the analysis in this way also presented an opportunity to examine how well Nussbaum’s universal list may be applied in a real life context.

Nussbaum’s (2007) List of Capabilities

- 1. Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.

- 2. Bodily Health.** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

- 3. Bodily Integrity.** Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

- 4. Senses, Imagination, and Thought.** Being able to use the senses, to imagine, think, and reason-and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic

mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid nonbeneficial pain.

5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)

7. Affiliation

A. Being able to live with and toward others, to recognize 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, and also protecting the freedom of assembly and political speech.)

B. Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of nondiscrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion,

national origin.

8. Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. Play. Being able to laugh, to play, to enjoy recreational activities.

10. Control over One's Environment.

A. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

B. Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

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Chapter Six: Study One - 1st results paper

Horrell, B., Stephens, C., & Breheny, M. (Under review). Informal caregiving for older people: using Nussbaum's central capabilities to understand care. Manuscript submitted for publication: *Scandinavian Journal of Caring Sciences*.

Abstract

Informal caregiving has been regarded as burdensome and viewed as an opportunity for personal development, indicating the complexity of providing informal care. To provide a more nuanced understanding of the experience of providing care for older people in the community, this study utilized a capability framework to examine informal caregivers' health needs. Drawing upon both Sen's (1980) and Nussbaum's (2007) contributions to the Capability Approach, we invited caregivers from New Zealand to participate in an Internet forum created specifically for the research. Nussbaum's list of central human capabilities was used as an a priori template for summarizing the data. This list provided a framework to examine and further specify capabilities within the context of informal care. The caregivers' responses corresponded with Nussbaum's list, and additional categories were not required, however, some capabilities were elaborated in terms of the caregiving context. Capability deprivation was a recurring theme in the caregivers' narratives; many of the capabilities were identified primarily by lack. Overall, the Capability Approach provided a valuable framework for understanding the health and support needs of informal caregivers' for older people.

Informal caregiving for older people: using Nussbaum's central capabilities to understand care

Introduction

Since the 1980s, capability has emerged as an alternative approach to evaluating human development (Haq, 1996), human well-being (Comim, 2005), and health (Venkatapuram, 2011). Having evolved within the context of welfare economics (Sen, 1980, 1992, 1999) and political and moral philosophy (Nussbaum, 2000, 2007, 2011), capability provides a theoretical framework for making comparisons about quality of life and wellbeing by considering the freedom people have to lead the kind of life they have reason to value (Alkire, 2007; Robeyns, 2006; Sen, 1999). According to the Capability Approach (CA), having the opportunity to select and achieve functionings (beings and doings) from a set of valued capabilities enables individuals to flourish (Alkire, 2007; Burchardt and Vizard, 2007; Nussbaum, 2000).

Assessing an individual's wellbeing requires some understanding of what they have reason to value (Sen, 1999), so a holistic approach integrating complex information to establish normative evaluations is central to the CA. However, Comim (2005) suggests that the CA struggles to handle multiple informational spaces, and this may account for the limited number of empirical studies using the approach. Beyond endorsing democratic process and public reasoning, Sen (2005) provides few specific details about how to collect relevant information to underpin capability evaluations. Nussbaum, on the other hand, offers a set of 10 central capabilities that she contends are "necessary conditions for a decently just society" (Nussbaum, 2007, 155). The 10 capabilities are: life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; play; other species;

and control over one's political and material environment. While these entitlements are "a set of fundamental entitlements of all citizens" (2007, 155), they are theory-based and highly abstract, and therefore require further specification according to local context. In this paper, we present the results of a qualitative study designed to identify the capabilities valued by informal caregivers for older people.

Informal Care

Informal caregivers are the mostly unpaid family, friends and neighbours of a care recipient who depends upon help with activities of daily living. The largest caregiving group provides care to older people. Most of this care is undertaken by adult children (mainly daughters) caring for parents and elderly women caring for their spouse or partner (Wolff and Kasper, 2006). Previous research has focused on the burden of informal caregiving (e.g. Pinquart and Sorensen, 2003, 2007), emphasizing the physical, psychological, social, and financial cost to caregivers' health (Feinberg et al., 2011). Informal care provision is an independent risk factor for mortality (Vitaliano, Zhang and Scanlan, 2003), and caregivers' failing health is a key reason for the institutionalization of care recipients (Spillman and Long, 2009).

Studies also document positive experiences associated with informal caregiving, such as acquiring specialized knowledge and skill, enhancing family relationships, life satisfaction, and personal growth (e.g. Carbonneau, Caron and Desrosiers, 2010; van Durme et al., 2012). Additionally, studies identify the multidimensional aspects of caregiving (e.g. Nolan, Grant, and Keady, 1996; Toljamo, Perälä, and Laukkala, 2012), reporting the co-existence of positive and negative experiences. These contradictory findings and the ambivalence associated with informal caregiving (Shim, Barroso and Davis, 2012) suggest that evaluating

informal caregiving needs to accommodate complexity (Balducci et al., 2008). In order to fully appreciate the experience of informal caregiving we need to examine caregivers' "real lives in their material and social settings" (Nussbaum, 2000, 1). Nussbaum (2000) identifies the morality of caring and the interdependent nature of care, in that it is both given and received, which follows an emerging perspective in the caregiving literature (Phillips, 2007). Nussbaum's list of capabilities reflects concern for the specific context of care and "provides the best framework within which both to value care and give it its necessary critical scrutiny" (Nussbaum, 2000, 244). The goal of this research was to understand the capabilities valued by people caring informally for older people in these terms.

Method

We utilized a hybrid methodology (van Ootegem and Spillemackers, 2010) that drew upon both Sen's and Nussbaum's contributions to the CA to engage a wide range of caregivers for older people in developing this knowledge. Acknowledging Sen's (1999, 2004) call for public, deliberative process to inform capability selection, our method involved creating an online forum, *carersvoicesnz*, for informal caregivers to discuss their experience of providing care for older people. Our deliberative, participatory approach aimed to educate the values of the informal caregivers whose lives were the subject of the research. Nussbaum's list provided a framework to analyze the caregivers' contributions to the forum. This was a bottom-up approach compared to studies that have used Nussbaum's (2000) list as the basis for deliberation (see Burchardt and Vizard, 2007; Wolff and de-Shalit, 2007). This study had Human Ethics Committee Approval.

The Internet has been identified as an effective means of accessing hard-to-reach populations (Levine et al., 2011), which includes informal caregivers. Using this method enabled participation from a nationwide catchment, allowing participants to join the forum

regardless of location or caregiving commitments. Additionally, the anonymity of the online format provided a space for participants to express themselves with less pressure to provide socially desirable responses (Authors, forthcoming). Utilizing the Internet as a vehicle for informal caregiving research removed some of the barriers to participation, and broadened access to informal caregivers' voices.

Recruitment

Organizations associated with caregiving and eldercare promoted the study in magazines and newsletters and on their websites and Facebook pages, including a hyperlink to the carervoicesnz website. Family members, particularly spouses, tend not to self-identify as informal caregivers when supporting someone with age-related disabilities (Dobrof and Ebenstein, 2003; Walker, 1995). To include those people, we also advertised on a website for people over 50 years, and an online auction website with a popular community message board. Considerable media interest in the study provided another source of recruitment (Authors, forthcoming).

Participants

Sixty informal caregivers from New Zealand took part in the study. They were all caring, or had recently cared for, someone in the community aged 65 or older. The participants' ages ranged from late teens through to mid-sixties, with two participants identifying as male. The participants included spouses, daughters, a son, a granddaughter, and non-kin caregivers; they provided care for people with various illnesses including Alzheimer's disease, Parkinson's disease, heart disease and cancer. Some of the care recipients had co-morbidities, and several caregivers were caring for more than one person.

Procedure

In the first week, the first author introduced herself to the forum and described her experience of providing informal care. She moderated the forum and initiated prompts in the form of discussion threads to stimulate discussion. These prompts were informed by both the caregiving and capability literatures. The forum was organized around four topics. In forum one, the participants described how and why they became caregivers; in forum two how they looked after themselves; and in forum three they discussed their experience of the caregiving process over time. In forum four, the participants introduced their own topics for discussion. The flexibility of the forum was a critical aspect that enabled participants to frame the research, contributing to a shift in power relations between the researcher and the participants.

Analysis

The forum posts were analysed using template analysis (TA; King, 2012). TA involves developing a coding “template,” to summarize the data. Analysis often starts with some a priori codes; and in this study the posts were coded according to the 10 central capabilities identified by Nussbaum (2007) as essential for human flourishing. In this analytic process the participants’ comments were treated as descriptive representations of their lives. The analysis does not examine contextual differences based on age, gender or ethnicity of informal caregivers.

Examples from the data are included in the results section, illustrating each of the capabilities in order, which enables readers to evaluate the analysis as suggested by Alkire (2007), and the appropriateness of the template for summarizing the data. Excerpts have been

reproduced as they were written, keeping the original spelling and grammatical constructions. Separate postings are joined by an ellipsis (. . .). The names referred to are pseudonyms.

Results and Discussion

Nussbaum's List

Our analysis showed that the participants' accounts supported the 10 capabilities identified by Nussbaum as valued requirements for wellbeing. Some capabilities were discussed more than others and, while some accounts showed the ways in which Nussbaum's list could be further specified, additional, distinct valued capabilities were not found. Capability deprivation (Nussbaum, 2000, 2007) was a recurring theme in the caregivers' narratives. The findings are thematically organized according to Nussbaum's (2007, 76-78) list of capabilities in the following discussion.

Life

The first of Nussbaum's 10 central capabilities is life. This entails having the capability to enjoy a good life of normal length, as opposed to having limited quality of life or having one's life prematurely cut short. Many caregivers expressed concern about their own life expectancy, as well as their life beyond caregiving. For example, Sarah described her children's discussion of how they would care for their father and grandparents should Sarah, the primary caregiver, die first. Sarah had recently visited the hospital emergency department with her sick husband, where the staff mistakenly assumed that she was the one in need of medical assistance. She concluded with the comment, "*When oh when will I get time to care for me??? Or will I depart this earth before that happens*". Such stories about self-neglect were posted repeatedly on the forum, and as Burchardt and Vizard (2007) have indicated, neglect of their own needs may ultimately deprive people of the capability for life.

Bodily Health

Nussbaum (2007, 76) identifies good physical health, being adequately nourished, and having adequate shelter, as important aspects of having the capability for bodily health. In this section we address each aspect, while suggesting two different ways in which Nussbaum's account could be extended to include mental health, and its application in developed countries.

Venkatapuram's (2011, 66) conceptualisation of bodily health includes, but is not limited to, having the "capability to avoid disease and impairments". The caregivers often mentioned having poor health, suffering particularly from stress and exhaustion. For example, Sally described health problems such as a torn bicep and damaged ribs due to lifting. She said, "*Caring for them both as in the end made myself have health problems... I get very stressed and it has increased my Blood Pressure*" (female caregiver for her mother and husband). In general, previous research shows that caregivers are more likely to suffer health problems. For example, more than twice as many co-resident UK caregivers suffer from poor health compared to non-caregivers (CarersUK, 2014). While Nussbaum includes having the opportunity to experience emotions, senses, imagination, and thought in her list, she does not explicitly address having the capability for good mental health, or the association between mental and bodily health. Joan's comment illustrated that, for these caregivers, the capability for health includes mental health, "*I would love to have someone come in for 1 1/2 hrs every mon to fri so that I could go to the gym... Exercise every day is a wonderful release and gives me the mental balance I need*" (female caregiver for her father). Regular exercise benefits mental wellbeing (Windle et al., 2010) and given that depression is significantly associated with caregiving (Jorgensen et al., 2010; Pinquart and Sorenson, 2003) this aspect of health is particularly relevant in the present context.

Nussbaum acknowledges that a lack of basic necessities may undermine bodily health, yet has very little to say about how this might apply in a developing nation (Gasper, 2014). While none of the caregivers in this study lacked adequate nourishment, several caregivers described needing to budget carefully and other ways in which food is important. For example, Dee described using her mother's money to buy small treats that she otherwise could not afford

I find pleasure in spending my Mother's money on small food items that I'd otherwise not include in my weekly shop. It makes me feel happy and rewarded when I purchase walnuts to add to a salad or top up with fresh fruit and produce midweek and I'm not paying for it (female caregiver for her mother).

In this sense, food is valued beyond providing adequate nourishment; food regarded as treats may increase a person's sense of wellbeing when perceived as a reward, whereas not being able to afford them engenders a sense of 'going without'. This suggests that once basic requirements have been satisfied, there are emotional qualities associated with nourishment that affect wellbeing and supports Gasper's (2014) argument that the CA may be utilized beyond poverty analysis, as a framework upon which to base any study of inequality.

Having the capability for bodily health also relates to having adequate shelter (Nussbaum, 2007, 76). This may be understood as having accommodation that is adequate for current needs (Anand et al., 2009), and provides a safe and pleasant environment (Robeyns, 2003). These participants focused on how their living arrangements had altered, or diminished as a result of caregiving. Many caregivers had either changed their living arrangements to accommodate the person being cared for, which included moving in with the person, or the care recipient moving in with the caregiver. Some had renovated their homes to make life

easier, safer, and more pleasant for themselves and the people they were caring for. Sally described this as having “all the devices in the house to make things easier”; Joan installed a ramp, “just in time as his [father] mobility has gone quite quickly!”; Kath decided to redecorate “as we both spent so much time indoors”; and Sarah described having to choose between leaving her home of 37 years or altering it so she could continue to care for an increasingly dependent husband who is more than twice her weight. All of these comments pointed to the value of living in a pleasant, functional environment.

Changes to living arrangements to accommodate caregiving could have both positive and negative consequences. Sally described relinquishing her office to create a room for her mother: “*I used to have my office, but thats mums room now*”. The internet has replaced her physical office space, becoming her “*own space*” where she can escape from caregiving duties. Otherwise “*The only time I have totally me time is when Im in the toilet, shower or asleep*”. Similarly, Sarah “discovered” the community message board on Trademe, an online auction site. Messaging community members provided her only “*time out...and a chance for conversation*”. She keeps her computer in a separate room, “*as coming here creates my own space [and] this quiet space is important to me*”.

Rose had lost contact with friends because a lack of privacy made entertaining at home uncomfortable. She shares the living room with her mother and has no separate entertaining area. This living arrangement also means that a potential relationship with a “man friend” has been unable to flourish, and she has found social space for herself outside the physical location of her home, “*Basically the phone, internet and libary are my best friends:]*”. In this respect, ‘space’ and ‘place’ become conflated, in the sense of being a physical space where caregiving and entertaining takes place, as well as a space to mentally and emotionally recharge.

Bodily Integrity

Bodily integrity refers to personal safety. It includes having the freedom to travel safely and having a choice in sexual matters (including reproduction). Nussbaum identifies domestic abuse as a particular example that threatens the capability for bodily integrity. In her story about caring for a husband with dementia, Kath raised this issue in terms of access to help when problems arose. Kath had planned to care for her husband at home. However

My husband's behaviour started to cause concerns for my safety... the agency stopped sending their staff as they were 'afraid', i myself felt threatened a couple of times...[he] was difficult at the day care as well...and at some point I realised that he was not wanted there anymore! This was a shock... (female caregiver for husband).

Domestic violence places informal caregivers at risk. More than a third of Cooper et al.'s (2008) study participants, who were caring for people with dementia, reported significant abuse from the people they cared for. Without adequate support, the bodily integrity of these informal caregivers is threatened, potentially affecting their capability for health.

Senses, Imagination and Thought

Nussbaum (2000, 2007, and 2011) foregrounds the arts in developing the capability for senses, imagination, and thought. Having these capabilities includes the opportunity to be educated; both scholastically and through extra-curricular opportunities. This study showed that a specific form of education, related to adequate understanding and preparation for the caregiving process, was important to the participants. Molly said “*Finding help for parents was like a needle in a haystack*”, and Margie described feeling isolated due to a lack of information, “*I am alone in this situation and aren't aware of who to turn to for help. I believe that govnt. departments do not advertise clearly enough what they can do to help*

people in these situations". Being able to access adequate information and education about their caregiving role is commonly cited as problematic for caregivers. A New Zealand study of informal caregivers' found that 96 percent of informal caregivers for older people were unhappy with the support and information that they received (Jorgensen et al., 2010).

Being able to enjoy "pleasurable experiences" (Nussbaum, 2007, 76) is another aspect of developing one's senses, imagination and thought. The participants' stories highlighted the negative effect of caregiving obligations on their capability for enjoyment. Sally described the sacrifices made while caring for her mother and husband, "*The only time I have had to myself in the last 2.5 years is to go to my school reunion. And even then I had to come home to check they were ok, make sure they got their meals etc*"; and Jo's remark, "*I haven't had the energy nor motivation to socialise*", indicates that having good health is associated with capability for pleasure. This illustrates Alkire and Black's (1997) observation that the achievement of functionings may depend on more than one valued capability.

Emotions

Nussbaum's conceives of emotions as "judgements of value" (Comim, 2014, 137) and includes "being able to have attachments to things and people outside ourselves" (2007, 76) as sub-category of the capability for emotion. Attachment (Bowlby, 1971/1980) is a close relationship linked with caregiving (George and Solomon, 1996), with emotions reflecting the "the state of a person's affectional bonds" (Bowlby, 1979, 130). Nussbaum also endorses affiliation as important for caring and family life. She describes affiliation, the seventh capability on her list, as "being able to live with and toward others, to recognize and show concern for other human beings" (2007, 77). The following excerpts highlight the considerable overlap between the capabilities for emotions and affiliation in the informal

caregiving context.

Positive regard for family members influences the desire to care for older people (Karantzas, Evans and Foddy, 2010). This is demonstrated by Anna who left her partner and 2 year old to care for grandparents in another city. Her commitment to their care was based on attachment and a sense of reciprocity for care she had received, as a child, from them

... both sets of grandparents had alot to do with our upbringing as my parents worked away from home alot, so to me i owed them that much they cared for me when i was a baby and a child and it was there turn when they got old and sick...I was with both when they passed away and i would do everything i did again and i would give up everything i did again in a heartbeat

On the other hand, she excuses her brothers' lack of involvement because they were too emotionally involved, "*my brothers found it hard and didnt like seeing him the way he was which i kind of understand he was like a dad to them*". This reveals two different dimensions of attachment from a caregiver's perspective. On one hand it can be positive, contributing to the desire to care for others, which in turn fosters emotional wellbeing because of personal satisfaction and increased self-esteem. On the other hand, it can include witnessing the suffering of an attachment figure, causing emotional pain. Pam acknowledges this ambivalence, "*I found it a privilege, I found it hell, I found it a time of great sadness and a time when I knew what we had done was the right thing*" (female caregiver for mother and father).

Many of the participant's displayed ambivalence towards caregiving. Over time, as they became more tired and stressed, positive feelings gave way to emotions such as

resentment because of having to cope without adequate support from other family members and health services; guilt for enjoying activities apart from caregiving, or without the person being cared for; and guilt for having negative thoughts about caregiving. For example, Dee described the anxiety she felt in trying to maintain the appearance of a stress-free environment to shield her mother from the impact caring for her had on the family. To some extent, Dee was deprived of the capability for “not having one’s emotional development blighted by overwhelming fear and anxiety” (Nussbaum, 2007, 77)

Caring for people with dementia is typically emotionally demanding, particularly as the disease progresses. Harriet said, *“It is sad to watch your husband forget how to do things like using a knife and fork, and I even have notes on all the doors as he does not know his way around the house, so have to guide him. He no longer knows my name”*. In this sense, caregivers grieve for the loss of the person they knew. As Chris commented, *“They don’t just die once they die many many times”*. While grief is an important emotion in the context of caring for older people, anticipatory grief is less well recognized. Frank’s (2008) finding that it is the combination of anticipatory grief and ambiguous loss, rather than hands-on care issues, which is most problematic for Alzheimer’s caregivers, suggests that as well as being able to grieve when the care recipient dies, caregivers need to be able to recognize and cope with anticipatory grief.

On the other hand, when asked how their expectations of caregiving may have changed, Jo said she had not expected it to be such a positive and rewarding experience. She described taking on the role of principal caregiver for her mother, who had terminal cancer, because she was between jobs and wanted to do something *“more meaningful than paper-shuffling”*. She thought if she could take over some of the menial tasks it would allow her mother to focus on fighting her cancer. What Jo had not expected was that caregiving would

enable her to *“give dignity to others, to help them out, to walk alongside them for a while. To experience connecting with a human on a real level”*. Jo’s comment reflects Quinn, Clare and Wood’s (2010) observation that caregiving has the potential to enhance personal development and substantiates Nussbaum’s argument that having the capability for human development through experiencing emotions requires *“supporting forms of human association that can be shown to be crucial in their development”* (2007, p,77).

Practical reason

Practical reason underpins the overall concept of capability and as such plays a special role as an *“architectonic entitlement”* (Nussbaum, 2007; 398). Nussbaum identifies practical reason as a way of expanding one’s capabilities in general, emphasizing the importance of having the freedom, or autonomy, to reflect upon, and make decisions about, what is important, which in turn enables the translation of capabilities into achievements, or functionings. Practical reason thus involves *‘being able to form a conception of the good and to engage in critical reflection about the planning of one’s life’* (2007, 77). Through comments such as, *“well done, you need a Gold Star!”*; *“you have done a great job”*; and *“you deserve a good life because you sound like a very good and caring person to me”* the participants in our study indicated that caregiving is a valued role and an achievement worthy of recognition and praise. In this respect, their conception of the good involves being a *“good carer”* (Pickard, 2010).

Several participants indicated that caregiving had been planned well in advance. For example, Anna *“promised my pop when i was 10 yrs old that he wouldnt go into a resthome”*. Similarly, Sarah recalled a conversation that took place on her wedding day: *“When I got married I had spent a couple of years working in a Geriatric ward so at my wedding I promised my in-laws that I would look after them when it was needed, my husband was an only child”*. According to Alkire and Black (1997) the purpose of practical

reasoning is to make intelligent choices about how to determine and use capabilities. Nussbaum (2000) suggests that this involves being able to use one's imagination in order to be able to engage in critical reflection about the planning of one's life. In other words, making life choices depends upon being able to imagine one's future. Joan's plans for the future involved buying a house with her father, "*Instead of him and I living in separate small dwellings we bought a huge modern home with a view*". Having become his caregiver she commented, "*What a good idea that was!* (female caregiver for father).

In contrast, Sarah cautioned against making plans and promises for the future, because what people imagine might happen and what actually happens may be quite different, "*A lot of us do that not realising the full implications and how our own lives change*". Pam's experience was of difficulties associated with day to day planning and a sense of not being in control. She said "*things that make caring more difficult are things that you can't control and those things you can't plan for*", and as a result, she had already started discussing her own care with her children, in the hope that they may learn from her experience and be less stressed as caregivers.

Informal caregivers' capability for practical reason, or decision making, does not simply reflect individual choice, but rather complex social interactions. For example, Kath described making a significant decision, at a crucial transition point typical of the caregiving process. She said that although "*Finding time to sleep became a problem, finding time to work became a problem, shopping became a problem*", she resisted outside advice to move her husband into residential care until she "*was forced to accept the rest home solution by the reality of the situation*". She said, "*I still feel guilty at times*". Kath's story highlighted that informal caregiving takes place within, and because of, relationships between the caregiver, the cared-for and the extended family, as well as formal, institutional relationships

with health-care professionals and service providers.

Nussbaum states that the capabilities on her list support one another in many ways, with practical reason and affiliation playing a significant role as they “organize and suffuse all the others” (2000, 82). In this study, the participants’ stories indicated that the capability for practical reasoning involves making choices based upon previous experience and inter-generational expectations, as well as being able to imagine the future. This highlighted the important role that emotions play in influencing decision-making and planning. Bearing in mind Nussbaum’s claim that people cannot function as dignified human beings unless they have the opportunity to exercise practical reason, or plan their own life, the association between informal caregivers’ affiliation and decision-making merits further investigation that also investigates the role of emotions (Authors, forthcoming).

Affiliation

Nussbaum (2000) accords a central role to the capability for affiliation, arguing that to function fully as a human being requires affiliation and reciprocity with others. This includes being able to “engage in various forms of social interaction” (Nussbaum, 2007, 77). A loss of social contact was reported in many of the participants’ stories. In one such example of capability deprivation, Dee described “*the opportunity cost of being a carer*”, in terms of affecting her ability to maintain former relationships. She said

I've got no friends. Did I ever really have any friends? No one now calls to talk to me, no one invites me out for any reason, none of them asks me if they can visit or help me in any way...this whole care giver experience has been insightfull in respects to all relationships I have (female caregiver for her mother).

Similarly, Jo stopped meeting friends socially; Sally’s friends stopped visiting; Sarah

reduced her involvement in church activities; and Kath reorganized her life as her husband's Alzheimer's worsened, meaning she could "*no longer socialise in any sort of normal way*", and she gradually withdrew from everything outside the house. Scott summed this up when he said, "*I get a very strong impression that most carers become isolated in about every aspect of life*". Social isolation has been identified in the psychological literature (Holt-Lunstad, Smith and Layton, 2010), epidemiological studies (Stansfeld, 2006) and studies of caregiving (Brodaty and Donkin, 2009) as a factor that contributes to poor health outcomes.

The participants described a varied quality of relationships with other family members. Some mentioned positive experiences of emotional support, "*all my siblings are incredibly supportive*", while others referred to a lack of support and consequently strained relationships. Rose said "*It has always fallen on me to give mum the support she needs, my brother could go six months without visiting and he lives in the same area*". Anna was the most vocal, describing her resentment at the apparent hypocrisy of family members who provided little concrete support but claimed a close relationship with the care recipient.

Because caregiving can create tension and conflict between family members, Nussbaum's observation that "institutions that constitute and nourish such forms of affiliation" (2007, 77) should be protected is particularly relevant in this context. Although some caregivers expressed appreciation for the support they received from various organizations, others struggled with the institutional response to informal caregiving. Doug described his attempts to get help for his mother as a "battle" with the medical authorities. He said, "*I had to ****fight**** both the GP and the District Nurses to get her catheterised so that both of us could get some normality*", summing up his experience as "*a challenge, having to fight at every step of the way to get assistance*". Doug's frustration stemmed from the inability of the medical profession to accept his first-hand knowledge of his mother's

condition, by treating him as if “*I did not know what I was saying*”. In this case it appears that Doug was not treated as a “dignified being whose worth is equal to that of others” (Nussbaum, 2007, 77), which relates to a second, more public aspect of affiliation: self-respect and non-humiliation. Being familiar with the person being cared for and having that intimate knowledge disregarded because it is deemed inferior to the expertise of health professionals is a form of humiliation. In spite of being expected to undertake on increasingly specialized medical tasks, informal caregivers may not be accorded the respect that they deserve. This is consistent with Jorgensen et al.’s (2010, 15) finding that caregivers need to be “supported and respected in our communities”. The role of institutions must be to “nourish”, not undermine, caregivers’ relationships.

Other Species

When Nussbaum talks about "being able to live with concern for and in relation to animals, plants, and the world of nature," (Nussbaum, 2007, 77) she is mainly concerned with the just treatment of nonhuman animals through the abolition of cruel practices, and envisages a world where all species will support each other and coexist in harmony. Of all ten capabilities on Nussbaum’s list this appeared to be the least relevant in the context of informal caregiving. Nussbaum has repeatedly said that her list has been designed to leave room for specification according to context and in this instance the findings showed that this capability is expressed by caregivers in terms of having an appreciation for, and being able to enjoy, nature. Jo highlighted the value of being able to take time out with her mother, “*sitting together outside, having a cup of tea, listening to the birds*”. Similarly, Scott appreciated being able to be “*outside doing ordinary things*” and chose to spend his respite care time in tramping as a way to “*recharge*”. However, he found it difficult to take time out from caregiving “*without feeling guilty*”. In this sense, this capability overlaps with the

opportunity to enjoy leisure activities.

Play

This capability relates to “Being able to laugh, to play, to enjoy recreational activities” (Nussbaum, 2007, 77). In the present study caregiving was associated with restricting or giving up activities previously enjoyed, including recreational activities outside the home. Being able to take a break had become increasingly difficult for caregivers like Theresa and Sarah who were not able to be away overnight. Theresa said “*I have restricted the time I am away from home. Also I cannot go away overnight or on holidays as I used to do*” (female caregiver for husband). Although respite care is available, this was not often used previously found in the literature (Berglund and Johansson, 2013; Vecchio, 2008). These participants suggested that it is not easy to access, is difficult to organize, too expensive, or not an option when care recipients refuse to have “*someone else to come in and look after them*”. Hospital stays provided Sally’s main form of respite. She said she was “*looking forward to the 6 days that mum will be in hospital for her opp. It will be a nice break for all of us*”. These caregivers also valued simple, everyday activities. For example, Scott tried to “*keep up a social night once per week with a group of men in the local tavern*” and wanted to be able to do “*ordinary things; people watching with a cup of coffee, watching a show & having a bit of a laugh*”. Several participants offered advice to others to “*Find a way to laugh and enjoy life*”. Being able to laugh, to play and to enjoy recreational activities was clearly valued, but the participants’ main focus was on limitations in their capability for play. Nussbaum (2000) argues that not having the time or energy for leisure activities also affects the capability for affiliation by restricting the opportunities for love to flourish through reciprocity, or social interaction. Similarly, Mausbach et al, (2011) found that being unable to take part in recreational activities threatens caregivers’ wellbeing,

and increases their risk for depression.

Control over One's Environment

Nussbaum separates having the capability for control over the environment into two distinct areas. The first relates to having the opportunity to participate in political processes. The second includes giving people a real opportunity to own property and to obtain meaningful employment. Many of the participants in our study described situations where they had lost control over their environment in some way because of their decision to provide informal care. Rose's story illustrated this as she disclosed the consequences of giving up paid employment to become an unpaid caregiver for her mother. Describing her transition into informal caregiving, Rose said

3 years ago she [Mother] ended up in hospital after a fall, at the time i had just sold my house and was temporally staying with her while I found somewhere else. The day she was discharged i got a call at work to come get her, she had told the staff i was living at her place and would give up work to look after her. So thats what i did,

Although she valued the opportunity to become a caregiver, choosing this role effectively reduced other choices Rose could make, and brought about her dependency upon the state as a "passive recipient of benefit" (Nussbaum, 2011, 30), because it was the only way she could manage financially. This also meant that Rose could not buy another home because her benefit payment was insufficient to meet mortgage repayments. Rose's situation is not unusual, as research shows that caregivers are often the less affluent and least well-organized in our society (Heymann, 2000) with fewer resources at their disposal to meet their caregiving needs.

Moreover, restricted opportunities, which were often portrayed by the participants in

this study as the outcome of providing informal care, may be viewed as a form of self-sacrifice which is accepted because of the love and commitment caregivers feel for the person being cared for. This indicates that decision making for informal caregivers cannot be reduced to a simple cost–benefit analysis and provides support for Nussbaum’s (2011, 38) observation that, even in more wealthy countries, people make ‘tragic choices’ whereby a plurality of commitment makes it difficult to make a choice that does not leave someone worse off. Nussbaum suggests that these types of conflicts provide an opportunity for social planning intervention.

Conclusion

Using Nussbaum’s list of central human capabilities as a template for analysis highlighted several aspects of caregiving experience. Firstly, the caregivers’ discussions about difficulties such as physical injuries, chronic illness, financial hardship, inadequate information from support agencies, social isolation, and giving up leisure activities were readily interpreted using Nussbaum’s capability categories. The information provided by the caregivers corresponds with Nussbaum’s list, which derives from independent philosophical argument. This endorses Nussbaum’s claim that her list “converges in many respects with what an informed desire approach could be expected to deliver” (Nussbaum, 2000, 119), and suggests that these central capabilities “are compatible with a wide variety of diverse ways of life” (Kleist, 2013, 266).

Secondly, some dimensions were discussed more than others in our sample. For example, access to information relevant to caregiving was discussed more than the capability to live in relation to other species. Some caregivers focused their posts on just one capability, suggesting that individual caregivers value capabilities differently. This supports Ootegem and Spillemaecker’s (2010) finding that people draw on their experiences of daily life when

making decisions about what is important to them. It also supports Sen's argument that capability is context dependent and therefore "the exact list will have to take note of the purpose of the exercise" (2005, 159). Overall though, the caregivers shared common experiences that corresponded with Nussbaum's list.

Nussbaum (2003, 33) argues that the capability concept can only work if there is a "definite set of capabilities". Her list of central human capabilities was constructed at an abstract level to stand apart from the variations of daily life (Anand et al., 2009), yet Nussbaum describes it as universally fixed and as open to modification. In this respect, these capabilities may best be understood as "important desiderata [rather] than as absolute requirements" (Gasper, 2014, 109) in providing a guideline for minimum social entitlements. In this sense, Nussbaum's list provides a methodological framework to examine and further specify capabilities within a particular context. We have identified several instances where using Nussbaum's list highlights particular capability restrictions in the context of caring informally for older people. The following examples show how the valued capabilities in regard to living arrangements and emotions may be interpreted in terms of support for caregivers, and highlight the context specificity of this approach.

The capability for adequate living arrangements has important implications for caregivers and suggests that Nussbaum's conception of adequate shelter may be further specified to reflect the ways that the home functions as respite as well as shelter. Firstly, caring for someone at home may necessitate physical changes to the environment as it evolves into a site for care. Secondly, sharing accommodation may confine caregivers in a gradually diminishing space physically and socially as opportunities to interact with others outside of the home diminish at the same time as space for respite within the home reduces. Interacting with others through the internet provides an alternative way of addressing

informal caregivers' social isolation. This "quiet space" enables the capability for affiliation with others, as well as the capability for play, both of which are important for emotional and mental wellbeing. Thinking about living arrangements in terms of interconnected capabilities extends the application of Nussbaum's list as a valuable theoretical framework upon which to structure detailed information relevant to a specific context.

Capabilities are not isolated, but interconnected and over-lapping. For example, we found that emotions play a significant role in caregivers' lives, across most capabilities especially with regard to their opportunity for freedom and practical reasoning. Although services, such as respite care and home help may have been available, the caregivers resisted help based on feelings of commitment to their role and concern for the wishes of the person being cared for. These findings suggest that thinking about informal caregiving in terms of providing extra resources may be inadequate, because the caregivers' emotions interact with the capability for practical reasoning thereby influencing the conversion of these resources into functionings, or actual achievements. Nussbaum (2011, 18) argues that "the crucial good societies should be promoting is a set of opportunities, or substantial freedoms, which people may or may not exercise in action". However the findings from this study suggest that social policy must consider resistance to these 'opportunities' and look more closely at the effects of overlapping capabilities in informal caregivers' lives.

Finally, while the capabilities valued by these informal caregivers correspond with Nussbaum's (2007) theoretical list, the qualitative, participatory method of identifying these capabilities was useful in deepening our understanding of the complexity of informal caregiving. In this sense, the list provided the means for, rather than the end of, the exercise (Gasper, 2014). Using emotions as an example, the participants' rich narratives highlighted that emotions suffuse and influence most capabilities. Some emotions were considered

more appropriate than others, and caregivers denied emotions that they perceived to be less socially appropriate. These findings demonstrate that it is not having the capability for emotions per se that is important in the context of informal caregiving, but rather how emotions are understood and managed. Having this information will lead to more appropriate support for caregivers.

Nussbaum's list establishes the minimum entitlements that should be guaranteed to each person, yet has the flexibility to be modified and enriched according to context. The capabilities on the list may be added to, but none may be taken away (Venkatapuram, 2011). The list may be successfully applied in different contexts, such as caring informally for older people, to identify valued capabilities. This study has identified that qualitative, participatory methodologies may be fruitfully used to develop the concepts of capability, and provide rich information about meaning and experience that can be utilised to focus future interventions and public policy.

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Link between Chapter Six and Chapter Seven

One of the key findings from using Nussbaum's list as a template is that the caregivers' stories and experiences did not fit neatly into the categories; rather, the capabilities were interconnected. The analogy that sprang to mind as I undertook the analysis was that the capabilities wove a tangled web as opposed to a linear list, supporting Venkatapuram's (2011, p. 162) argument that the "the [Capability for Health] CH, and indeed every capability, is really a cluster of iterative capabilities and functionings". This highlights the multidimensional nature of capability, exemplified by Nussbaum's inclusion of sub-categories for each capability on her list. Because capabilities overlap and interact in multiple and complex ways, we need to go further than simply listing those that are valuable in order to understand diverse experiences.

An important feature of Template Analysis (TA; King, 2012) is that "it encourages the analyst to develop themes more extensively where the richest data (in relation to the research question) are found" (Brooks et al., 2014, p.4). The first level of analysis in Study One identified emotions as an integrative theme (King, Carroll, Newton, & Dornan, 2002), in the sense that this aspect of the caregivers' lives infused the discussion no matter which capability was being discussed. The following manuscript expands upon this by considering the interconnected nature of capabilities and the significance of emotions. Using the concepts underpinning the CA, the analysis moves beyond a realist, or positivistic, level to a second more interpretive iteration. This illustrates that the CA may be utilised to expand upon descriptive information to provide deeper insight into a specific context. The more detailed, contextual data from the online forum indicates, to borrow from gestalt psychology, that the whole is greater than the sum of each separate capability. In this respect,

Venkatapuram's (2011) conception of health, as not just the absence of disease but having the opportunity to achieve a cluster of vital goals, is well positioned to account for this complexity.

On a personal level, a key moment in the analysis occurred at this stage of the study. My mother was hospitalised and her requirements became my first priority. I had to attend to her needs in hospital as well as maintain the practical aspects of her home life – paying bills, changing appointments, tending the garden and keeping her friends updated with progress reports. I assumed total responsibility for my mother's affairs, putting myself in her shoes and anticipating what needed to be done next, while also attending to my own household and other family members. However, the practical tasks were easily managed compared to the emotional energy that was invested in her care. I found that this aspect of her care left me physically and mentally drained, which was also reported in the lives of the study participants.

Having begun the study thinking that I would be writing about how the demands of the practicalities of caregiving impacted caregivers' health, I found myself instead reading about caregivers' feelings and choices. While the participants' situations were varied and their experiences not necessarily the same as mine, the data reflected back what was happening in my own life and suggested that emotions play an important role in the lives of informal caregivers for older people. This experience impacted my analysis of the data in several ways. Firstly, it advanced my awareness of the demands faced by caregivers, and particularly those who are long-term caregivers. Secondly, I became acutely aware of the emotional complexities associated with caregiving. As my initial feelings of concern became tempered with ambivalence, I realised how emotional involvement can lead to mental and physical exhaustion. This increased my empathy for the caregivers in the forum and enabled

deeper insight into their experience. The positive side to this is that it may have enriched the analysis and enabled me to consider things I might otherwise have missed. On the other hand, it made me think about what I was bringing to the study and how my own experience might 'colour' the analysis. While it was difficult to objectively remove myself from the analytical process, I tried to be reflexive and manage the situation as best I could. As a result, I re-visited the analysis some months later, in order to approach it with 'fresh' eyes. After working through the data a second time, my overall findings remain virtually unchanged.

In the following chapter, the findings from a second analytic iteration of the data, which took an interpretive approach to analysing the theme or capability for emotions, are presented.

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Chapter Seven: Study One - 2nd results paper

Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. *Health Psychology, 34(4), 339.*

Abstract

Objective: The study investigated the capabilities important to the health of people caring informally for elders. **Method:** Over four months, 60 informal caregivers from New Zealand participated in online discussion boards which provided a set of virtual forums. It drew upon the Capability Approach (CA; Sen, 1980) to frame a qualitative inquiry whereby participants could anonymously respond to an evolving joint discussion of their health needs. Template analysis based on Nussbaum's (2007) list of essential human capabilities informed the thematic analysis. **Results:** The results showed the interconnected nature of capabilities and the importance of emotions in informal caregiving. Emotional attachment influenced the caregivers' freedom to choose how they lived their lives. Because they valued the capability to care for loved ones, the caregivers traded other capabilities, putting their lives on hold, and compromising their wellbeing. **Conclusion:** The self-abnegation reported by the caregivers highlighted the relational nature of caregiving and challenged a dominant perspective in the caregiving literature that focuses on the burdens of caregiving. The significance of emotional aspects related to the valued capabilities of caregiving suggests the need to acknowledge caregiving as an interdependent relationship and emotions as a crucial place to focus future support for caregivers.

Capability to Care: Supporting the Health of Informal Caregivers for Older People

Introduction

Care for elders is an issue of pressing social concern that threatens to overload the healthcare system (Kittay, Jennings & Wasunna, 2005). To date, notions of choice, independence and ageing-in-place dominate social policy solutions to the “care crisis” (Kittay, 2013, p.73), both as a means to maintain wellbeing for elders and to reduce the financial burden associated with residential eldercare. The social policy focus on independence ignores the inevitable physical decline of ageing and has significant implications for care relationships as people age (Breheny & Stephens, 2012). Remaining independently at home requires significant levels of community care, particularly amongst the oldest-old, and takes for granted the availability of informal caregivers to provide such support (Hale, Barrett & Gauld, 2010). This traditional solution to eldercare is problematic, because family and social structures have changed. Blended and geographically dispersed families and women’s participation in work outside the home alter familial availability and willingness to care (Hooyman & Kiyak, 2011).

Informal caregivers are mostly unpaid family, friends and neighbours of a care recipient who requires help with activities of daily living. The largest caregiving group is adult children (mainly daughters) or elderly wives, caring for a spouse or partner (Schofield et al., 1997). Informal caregivers provide as much as eighty percent of community care. The per annum cost of replacing this unpaid care with paid formal care is estimated to be around £119 billion in the UK (Buckner & Yeandle, 2011).

Set against the societal financial advantages of informal caregiving, are the costs to the caregiver. More than 30 years ago Zarit, Reever and Bach-Peterson (1980) used the term

‘caregiver burden’ to describe the strain associated with caregiving. Since then, caregiver burden has been studied as both a predictor for poor health and an outcome of the caregiving process (Savundranayagam, Montgomery, & Kosloski, 2011). Research framed this way, indicates that caregiver burden negatively influences the physical, psychological, psychosocial, social, and financial health of caregivers (Feinberg et al., 2011), and cites caregivers’ failing health as the main reason for the institutionalisation of care recipients (Spillman & Long, 2009). Informal care provision is thus associated with adverse health, and is an independent risk factor for mortality (Schulz & Beach, 1999).

Alternatively, positive experiences associated with informal caregiving have been reported, such as acquiring specialized knowledge and skill, enhanced family relationships, life satisfaction, and personal growth (Carbonneau, Caron & Desrosiers, 2010; Post, 2007; van Durme et al., 2012). Van Groenou, de Boer and Iedema (2013) attribute this apparent ambiguity to comparisons between different dimensions of caregiving and different types of care relationships, suggesting that individual differences may explain contradictory experiences. However, studies concerned with the multidimensional aspects of caregiving, document co-existent positive and negative experiences (e.g. Lopez, Lopez-Arrieta & Crespo, 2005; Nolan, Grant, & Keady, 1996; Toljamo, Perälä, & Laukkala, 2012). This highlights the ambivalence associated with informal caregiving (Shim, Barroso & Davis, 2012), supporting Balducci et al.’s (2008) review of the COPE Index, which suggests that assessment tools should reflect such complexity. These studies add balance to the literature on informal caregiving; however, burden and strain remain the dominant focus of informal care research.

While Brown and Brown (2014), among others, contest the extent of caregiver burden, the on-going research focus on burden has stimulated the development of

interventions such as counselling, support groups, and respite care as coping strategies for caregivers. Yet, despite increased support for caregivers, these solutions are not always well utilized (Di Rosa et al., 2011; Foster, Layton, Qualls & Kebe, 2009; Montgomery & Kosloski, 2013). Various reasons have been suggested for this, including limited knowledge of services, or difficulty accessing services, and reluctance to accept help, particularly when it comes to entrusting loved ones' care to strangers (Hooyman & Kiyak, 2011).

Furthermore, those most in need of help are likely to disengage from sources of social support (García - Alberca et al., 2012). Nolan et al., (1996) describe the acceptance of support as a balancing act, whereby caregivers weigh up the benefits for themselves against the drawbacks for the cared-for person, and feelings of guilt for relinquishing care, albeit temporarily. Assistance is mostly provided as an institutional universal service that neglects the social context of caregiving (Brown & Brown, 2014). Stoltz, Lindholm, Udén and Willman (2006) argue that support should meet caregivers' particular needs, which requires strengthening relationships between caregivers and health professionals. Similarly, Toseland, Haigler and Monahan (2011) suggest that caregiver education and support programmes that include family, friends, and family issues would better address the needs of informal caregivers. While Larkin and Milne (2014) acknowledge a shift in awareness of the caregiving role and caregivers' needs, they argue that there is still a long way to go in the quest for caregivers' empowerment. Focusing on the interdependent and relational nature of care is suggested as a possible way forward.

Caregiving develops within relationships and over time. Informal caregivers may be thrust into a caregiving situation unexpectedly or experience a gradual transition into providing care, for example in the case of progressive, chronic illnesses such as Parkinson's and Alzheimer's disease. When supporting someone with age-related

disabilities, like sensory loss or arthritis, women in particular perceive their actions as normal, everyday activities inherent in a long-term family relationship (Walker, Pratt, & Eddy, 1995). In this respect, caregiving is commonly perceived as ‘women’s work’ and largely invisible to society. Informal caregivers who do not self-identify as caregivers are unlikely to avail themselves of support interventions (Montgomery & Kwak, 2008), often waiting until they are unwell before seeking help. This increases informal caregivers’ vulnerability to poor health and the risk of becoming “hidden patients” (Criel et al., 2014; Fongler & Goodrich, 1979; Pinquart & Sörensen, 2007).

Focusing on the individual neglects the complexity of informal caregiving. This complexity includes differences in the caregiver-recipient dyad, as well as contextual factors such as personal histories and particular circumstances, and the broader relational and socio- historical context of caregiving. The broader context takes into account socio-cultural expectations and systemic inequities such as inequalities arising from gender, socioeconomic status, and ethnicity. In order to fully appreciate the experience of informal caregiving we need to examine caregivers’ “real lives in their material and social settings” (Nussbaum, 2000, p.1).

The Capability Approach

Nussbaum argues that the Capability Approach (CA) “provides the best framework within which both to value care and give it its necessary critical scrutiny” (Nussbaum, 2000, p.244). The CA (Nussbaum, 2000; Sen, 1980) is concerned with the freedom people have to lead the type of life they have reason to value, thus providing a useful basis for examining health (Venkatapuram, 2011). The CA considers people’s ability to live well across all spheres of life, scrutinising not only personal characteristics but also the political, social and economic environment. To advance social justice, Nussbaum (2007) has formulated a list of

ten capabilities that she believes are essential for human flourishing. Derived from philosophical principles and grounded in experiential knowledge, these capabilities are: Life; Bodily health; Bodily integrity; Senses, imagination and thought; Emotions; Practical reason; Affiliation; Play; Other species; and Control over one's political and material environment. Using these principles as the basis to study informal caregiving has the potential to advance caregiving research beyond the simple dichotomy of informal care provision as either burdensome or rewarding by integrating contextual understandings of care with personal values.

Sen (2004) believes that capabilities are context-specific, and therefore a process of democratic deliberation should inform decisions about their importance. In other words, people should be given the opportunity to decide which capabilities are valuable to them. According to the CA, individuals flourish when they have the opportunity to convert their valued capabilities into actual achievements, or "functionings" (Nussbaum, 2000). Rich, contextual information aids understanding of this process, because people have different abilities, in different contexts, to convert capabilities into actual achievements (Sen, 1985). To that end, this study uses an innovative methodology, inviting caregivers to participate in developing knowledge of their particular health context. Focusing on caregivers' capability, or what they are able to be and do, and how that affects their own health, shifts the lens from the costs and rewards of caregiving and examines what informal caregivers value. This in- depth qualitative inquiry into caregiver's health needs asks: which capabilities are important in informal caregivers' lives?

Method

Methodology

Sen's (2004) focus on identifying capabilities through deliberative democracy was a fundamental principle underpinning our decision to create an online forum that would enable geographically dispersed caregivers to join together as a community of interest for the purpose of engaging in "democratic dialogue" (Heron & Reason, 1997, p.8). This dovetails with the concepts of participatory research which involves participants in the creation of knowledge which is grounded in the participants' first-hand experience (Nind et al., 2013). A key characteristic of participatory research is emergent design (Herr & Anderson, 2005), which accords with the hybrid approach (van Ootegem & Spillemaecker, 2010) utilized here. In this study, Sen's CA provides the overall framework for the project, and informs the choice of a participatory methodology; Nussbaum's capability list provides the template for the first iteration of analysis; and the second more interpretive layer of analysis incorporates the theoretical underpinnings of the CA. The aim was to create a capability list specific to the values and health needs of those providing informal eldercare.

Participants and procedure

Informal caregivers throughout New Zealand were invited to join the online forum, *carersvoicesnz*, which was created specifically for the study. The decision to use the Internet may be considered a limitation of the study because it excludes caregivers who do not have Internet access or the required level of computer literacy. However, utilising the Internet as a vehicle for research provides flexibility and convenience that removes other barriers to informal caregivers' participation in research using traditional methods. For research purposes, informal caregivers may be understood as a difficult to reach population

(Fredriksen-Goldberg & Hooyman, 2007). Caregiving responsibilities may limit their ability to engage in research both at home and away from home. Additionally, time demands and the unpredictable nature of providing care may make it difficult to accommodate research at home at a pre-arranged time. Using the Internet for research therefore has the potential to broaden access to caregivers' voices in research about care provision.

Because the Internet has been identified as an effective means of accessing hard-to-reach populations, we utilized the World Wide Web for recruitment. The participants were recruited via the various websites and networks of New Zealand caregiver organisations, caregiver support groups, and organisations associated with the chronic illnesses of old age. Additionally, because family members, and particularly spouses, tend not to self-identify as informal caregivers when supporting someone with age-related disabilities (Dobroff & Ebenstein, 2003; Walker, 1995) and are therefore not affiliated with caregiver networks, we extended recruitment beyond caregiving networks by advertising on a website for people over 50 years, and an online auction website with a substantial membership and community message board, to reach younger caregivers. The online auction site proved to be a very useful method of recruitment and data collection. Considerable media interest in the study provided additional promotion. The recruitment method could be considered an online version of snowball sampling (Sadler et al., 2010), in that support organisations and message board members acted as intermediaries to source potential participants and promote carersvoicesnz. As the design includes only those participants who had Internet access, and who self-identified as informal caregivers, the results of the study should be interpreted as an account of informal caregiving that relates to this specific group of caregivers.

Over four consecutive months, during 2010 and 2011, 60 caregivers took part in the discussion. To protect their anonymity, the caregivers used pseudonyms and were not asked to provide demographic details. However, the contextual background details contained within the participants' postings elicited some demographic information which revealed that the ages of the participants ranged from late teens through to mid-sixties, and only two of the participants identified as male. The caregivers included spouses, daughters, a son, a granddaughter and unrelated volunteers. They were providing care for people with various chronic illnesses associated with ageing including, Alzheimer's disease, Parkinson's disease, heart disease and cancer. The discussion became a set of 'virtual' forums that provided the opportunity for informal caregivers to interact with each other and with a researcher as moderator. The forum participation mirrored focus groups in that some participants engaged fully; interacting with others and repeatedly posting comments, while others played a lesser role in the discussions, and of course, there may have been those who just observed or 'lurked'.

The forum was not conducted in real time. Because of the personal time commitment of caregiving, the website was set up to enable participation at the most convenient time for each caregiver. Via discussion boards, caregivers were invited to contribute what they considered important for maintaining their own health while providing eldercare. Questions posed by the moderator were informed by the caregiving literature and framed in the language of capability, reflecting the concepts of opportunity, freedom, and agency. The forum was organized around four topics, which in effect became four virtual forums. In forum one, the participants were invited to describe how and why they became caregivers; in forum two how they looked after themselves; and in forum three to discuss their experience of the caregiving process as it changed over time.

In forum four, the participants introduced their own topics for discussion. These procedures were approved by the University Human Ethics Committee.

Analysis

The data were analyzed using template analysis (TA; King, 2012), a type of thematic analysis used to analyze qualitative data. It is both structured and flexible, in that it can be adapted to suit a particular study. TA involves the development of a coding "template", to summarize important themes. Analysis often starts with some a priori codes; and in this study these codes were the ten central capabilities identified by Nussbaum (2007) as essential for human flourishing. Nussbaum's list was chosen because it reflects her awareness of, and concern for, the specific context of care.

The first step in the analysis, conducted by the first author, was to read through the data and code the excerpts according to Nussbaum's list. In this process the participants' comments were treated as descriptive, factual representations of their lives. We were interested in the caregivers' experiences in general and because we had made the decision not to collect demographic details, the analysis does not extend to examining contextual differences based on age, gender or ethnicity. The excerpts were able to be coded to more than one capability, demonstrating that capabilities are not separate; rather, they are interconnected.

While Nussbaum's capability list provided an appropriate template for coding, stopping the analysis at that point would not have done justice to the information contained in the caregivers' postings. The caregivers' postings were both spontaneous and reflective, including long narratives that had been composed with a great deal of thought. The comprehensive detail provided a richness that contributed to an overall narrative

about caregiving. Therefore, a second iteration developed the initial coding template, utilising the concepts underpinning the CA. This second round of analysis focused on emotions and how they affect caregivers' freedom to pursue the central capabilities presented in the list.

Feminist care theory raises concerns about the gendered nature of care, socio-economic status and other structural inequalities that affect informal caregivers' lives. Sainsbury (2013) has identified two theoretical strands that have implications for this analysis. The first views care as a moral responsibility inherent in an interdependent relationship (e.g. Tronto, 1993). The second is 'rights' based (e.g. Knijn & Kremer, 1997), which conceptualizes caregivers as citizens who have the right to support should they choose to provide informal care, or the right to choose not to provide care in favour of pursuing paid work. Undertaking paid work is perceived as a means to achieving financial security and independence, thereby addressing inequalities associated with gender and power relations. While acknowledging that these are important issues that affect caregivers' control over their own lives and are therefore worthy of analysis, the participants' stories in this study resonate most closely with the first viewpoint, which is reflected in the following analysis. The codes and their relationship to the themes described in the findings were discussed and revised among the three authors.

Presentation of results

Wherever possible, excerpts have been reproduced as they were written, with the original spelling and grammatical constructions. One of the pitfalls of working with a pre-existing template is the temptation to 'force' the data into the categories. To enable readers to evaluate the analysis and the evidence for the claims made, the analyst's partial perspective and reasoning is made explicit and defended, while a collaborative reading of

the ‘raw’ data facilitates future discussion of the findings (Alkire, 2007). Some of the extracts reproduced below are a compilation of thematically similar comments from different postings by the same caregiver. Separate postings are joined by an ellipsis (...). This does not change the meaning of the excerpts included. The names referred to are pseudonyms.

Results and Discussion

Capabilities in the Context of Caregiving

Employing Nussbaum’s (2007) list of central human capabilities as a template confirmed that these universal principles are relevant in the context of informal care. The ten capabilities are: Life; Bodily health; Bodily integrity; Senses, imagination and thought; Emotions; Practical reason; Affiliation; Play; Other species; and Control over one’s political and material environment. The coding process highlighted a diverse range of experiences but illustrated common values. For example, the caregivers valued having access to timely and appropriate information, and being respected for their expertise and knowledge about the needs of the person being cared for. They wished to have time to themselves and with friends and the time or energy to pursue activities outside caregiving. Less commonly, but certainly no less importantly, they wished to have support to keep safe from abuse.

Referring to Nussbaum’s list demonstrated that the caregivers discussed some of these central capabilities more than others, and valued capabilities were mainly identified through the participants’ talk about not having them. Discussions about health focused on the frustrations of poor health exacerbated by caregiving:

Caring for them both as in the end made myself have health problems. I have

had a heart valve replacement so have to deal with the heart stuff. I have trouble with my ribs still especially if I need to help them both stand up etc. I tore my bicep muscle pulling mum off the dining chair and I still have trouble with that (Sally, female, caregiver for husband and mother).

Material wealth was invariably couched in terms of financial strain, “*I no longer have financial peace of mind or freedom to do activities I’d normally do*” (Dee, female, caregiver for her mother). The importance of friendships was identified through postings about losing contact with friends because of caregiving. For example, Dee describes “*the opportunity cost of being a carer*” in terms of not being able to maintain former relationships:

I’ve got no friends. Did I ever really have any friends? No one now calls to talk to me, no one invites me out for any reason, none of them asks me if they can visit or help me in any way... So this whole care giver experience has been insightful in respects to all relationships I have

Hale (2000) describes caregivers’ changing social networks in terms of making of new associations with health care professionals and other caregivers as former friendships recede. If the opportunity to forge and strengthen wider relationships is not available then informal caregivers risk feeling burdened, abandoned and socially isolated.

Overall, the participants’ stories provided support for using capability as a means of framing the experience of informal caregiving on individual, relational and socio-historical levels, with Nussbaum’s central capabilities list providing a useful foundation from which to build a more fine-grained analysis.

Capability, caregiving and emotions

The second stage of analysis explored the interconnected and over-lapping nature of capabilities, as described by our participants, in more depth. In particular, the participants' stories indicated that emotions weave their way across other capabilities, creating an interconnected web. For example, emotional attachment informs the capability for practical reason in relation to the freedom caregivers have to make choices throughout the caregiving process. These choices affect aspects of the caregivers' lives such as living arrangements, leisure activities, employment options, and most importantly health. In this way emotions are strongly inter-twined with how caregivers experience caregiving and manage their daily lives. These emotions form the basis of a complexity which underpins caregivers' attempts to achieve valued capabilities.

The capability to care

Our analysis highlighted the overarching importance of having the 'capability to care' based on a shared personal history with the person receiving care. These caregivers describe positive regard for the care recipient and demonstrate a commitment to caregiving based on feelings of love and empathy as well as reciprocity or 'giving-back' for caregiving received in the past. This suggests the need to consider caregiving, at the very least, in terms of a caregiving-receiving dyad (Hooyman & Kiyak, 2011). In general, the participants' comments highlight the personal meaning associated with caregiving and the emotional investment in terms of attachment (George & Solomon, 1996).

Anna's story demonstrates the enduring aspect of attachment and how roles reverse as a formerly dependent child assumes the role of protector and caregiver:

...at 17 with a 2 year old and a partner working i didnt think twice about going to

care for my dad's mum and my mums dad ... both sets of grandparents had alot to do with our upbringing as my parents worked away from home alot, so to me i owed them that much they cared for me when i was a baby and a child and it was there turn when they got old and sick...I was with both when they passed away and i would do everything i did again and i would give up everything i did again in a heartbeat (female, recent caregiver for her grandparents).

Attachment to a care recipient may be experienced in different ways. For example, Joan describes being “*so happy*” caring for her father over the last 2½ years. She prefers the option of caring for her father at home and, like many of the participants, Joan justifies her resistance to making the transition into residential care in terms of her emotional attachment to the care recipient “*no matter how plush the latest Rest Home is or how many recreational activities provided they will not be able to give the love that family can*” (female, caregiver for her father). On the other hand, Pam’s comment alludes to the emotional pain of witnessing the suffering of a loved one, which is typical of the mixed emotions described by many of the participants, “*I found it a privilege, I found it hell, I found it a time of great sadness and a time when I knew what we had done was the right thing*” (female, caregiver for her mother and father).

These comments illustrate the relational nature of caregiving, and focus our attention on the care recipient as somebody to whom caregivers are emotionally attached. This contrasts with consideration of the person being cared for as an anonymous burden from whom the caregiver deserves respite and relief. However, the commitment to caregiving also shapes decision-making and affects caregivers’ freedom to be able to do the things that they would like or need to do for themselves.

Conflicting emotions

Despite their emotional investment, the caregivers' postings indicate the ambivalence, which has previously been associated with caregiving (van Gaalen, Dykstra & Kompter, 2010). Relationships with the care recipient inevitably change over time, as well as relationships with other family members. The caregivers discussed emotions of frustration, resentment, grief, longing, and anger. Sarah introduced the topic entitled 'Resentment' in forum four:

I some times wonder if what I have been doing by being the caregiver whether I am doing it out of a sense of duty or because of love. As the oldest of five children it was an expectation that I would care for them from a very young age... Some of this caregiving was overlapping as it comes to 70 yrs. feels like 80 but I have just turned

64. When oh when will I get time to care for me??? (female, caregiver for father and husband).

Throughout the forum Sarah discussed her lifetime role as a caregiver for her siblings, her children, her parents, her in-laws and her husband. Although she says she always wanted to be a nurse, she feels frustrated by the assumption from other family members that she is able to take full responsibility for the care. This theme was picked up by other caregivers, like Diane, in relation to the expectation that they would provide care and feeling the burden of being the primary caregiver:

I view other extended family members differently often feeling resentment towards them for calling once a week to find out how Mum is doing and once again telling me all the reasons they can't help - yes I know (female, caregiver for her mother).

Diane and Sarah's comments suggest that other family members, who would be equally well placed to provide care, choose not to. This arouses negative feelings that are not directed towards the caregiving role per se, or the person receiving care, but rather towards the social expectations around who should provide the care, and the expectations on some particularly women, to take more responsibility than they felt was fair. Expectations based on experience of intergenerational relationships, which influence the decision to care, are shown in Milly's comment:

"Mum cared for both her mother and my dad, at home and at various times, until their deaths" (Milly, female caregiver for her mother).

These expectations which, in Milly's case, supported feelings of attachment and willingness to care could also foster feelings of resentment and frustration when imposed by others. Thus, the importance of attachment in caregiving is moderated by feelings of being unfairly overwhelmed with responsibility due to others' assumptions and expectations.

Kath's story highlights the emotional turmoil underlying caregivers' decision-making at important transition points as she describes events leading up to the eventual placement of her husband in fulltime residential care:

Doctors and advisors started talking about a rest home but I did not think it was a good option at all. Still my son and i visited a rest home with a dementia unit and i honestly was terrified at the thought of leaving my husband in a place like that. As my husband could no longer communicate with others in a meaningful way, all decisions had to be mine. I decided to keep up doing what I was doing for as long as I could. And i did... I was happy, I felt i was doing

the right thing...Unfortunately things got worse. Finding time to sleep became a problem, finding time to work became a problem, shopping became a problem, the agency stopped sending their staff as they were 'afraid', i myself felt threatened a couple of times. My husband's behaviour started to cause concerns for my safety, my family and the medical profession advised to think about a rest home (specialized for dementia care)... Eventually I was forced to accept the rest home solution by the reality of the situation. I still feel guilty at times (female, caregiver for her husband).

This story reflects the complex issues that informal caregivers face with regard to planning and decision-making, or having the capability for practical reason. Being an informal caregiver goes beyond helping with the activities of daily living. Caregiving takes place within, and because of, on-going personal relationships between the caregiver, the cared-for and the extended family, as well as formal, institutional relationships with health-care professionals and service providers. Thus, for informal caregivers, decision-making does not simply reflect individual choice, but rather complex social interactions and institutional provision. Kath's sense of guilt may have been eased if her decision to place her husband in care had been based on choosing a more welcome alternative to home care, rather than a place where she was "terrified" to leave her husband.

Many of the caregivers mentioned guilt in relation to both negative and positive feelings. For example, Scott says that it is "normal to feel resentfull, angry etc.", but he admits that he finds it difficult to enjoy activities, that non-caregivers might take for granted, without feeling guilty, "The need I have is for time outside doing ordinary things; people watching with a cup of coffee, watching a show & having a bit of a laugh and importatly all without any feelings of guilt and there lies the catch!!" (male, caregiver

for his wife). Guilt was often discussed in relation to life outside caregiving. Kath describes leaving her husband at day care, which gave her a “*taste of freedom*” but at the same time it made her feel guilty “*as I enjoyed it so much*”.

Researchers have suggested that caregivers tend to provide socially desirable responses in research about themselves. The tendency for informal caregivers to hide negative feelings associated with caregiving has been discussed in terms of their wish to be perceived as ‘good carers’ (Pickard, 2010). BurrIDGE, Winch and Clavarino (2007) attribute this to the contemporary cultural context for caregiving in which the expression of negative feelings towards providing informal care may be interpreted as a transgression of social norms. In our study the anonymity afforded by the online format provided an opportunity for participants to express negative thoughts without fear of judgement. Rather than expressing a general reluctance to care, or the feeling that there was no other option, negative comments related mainly to difficulties experienced during the caring process, after the choice to care had been made. For example, caregivers discussed hiding their negative thoughts and emotions to protect the feelings of the care recipient or other family members. Dee talked about not wanting her mother to feel that her care is burdensome, while simultaneously feeling that Dee’s caregiving role places a burden on her husband, who works up to 60 hours per week to support the extended household. A lack of financial security, guilt and trying to maintain the appearance of a stress-free environment cause Dee anxiety:

Having real freedom from financial worries brings a peace of mind which benefits my household environment. With money everything becomes easier thus everyone is happier, smiles more, laughs more, and we relax more together. This environment is the sort of home I want to create for my Mother not one whereby

she witnesses how stressed we often are... I never mention my feelings because I don't want to cause [husband] additional worries (female, caregiver for her mother).

The study participants portray themselves as nurturers, protectors and problem solvers who put others' needs before their own. Despite their frustrations and sacrifices, having the capability to care is important to these participants. Feminist research draws attention to caregiving as an essential and worthwhile part of people's relationships, while pointing out the lack of value that society as a whole places on the work of informal caregivers, and the marginalisation of informal care in social care practice (Barnes, 2012). Thus, caregivers value being able to care for loved ones, feeling that what they are doing is valuable, yet they lack wider support for their role as informal caregivers.

The participants' accounts illustrate the interconnections between the capabilities identified as important for informal caregivers' health. The capability for emotions weaves these capabilities together. The caregivers' describe both positive and negative emotions, highlighting the ambivalence and tension inherent in caregiving. Some emotions are considered more appropriate to express than others, for example compassion and grief are more readily discussed than anger and resentment. Participants are willing to describe the experience of happiness and joy in the context of caregiving, but talk about guilt suggests they are reluctant to admit they enjoy activities outside of caring. The emotional effort expended as caregivers attempt to hide or deny negative feelings in order to meet their own and others' expectations, as well as to protect others, may compromise their capability for health. Additionally, the belief that being a good caregiver involves putting their own feelings to one side, because the needs and feelings of the person being cared for come first, restricts the caregivers' freedom to choose other capabilities. In this

sense, the capability to care involves trade-offs.

Trade-offs

Although informal caregivers value other capabilities, the caregivers in this study repeatedly demonstrated that they were prepared to forego or trade them in order to be caregivers. The extent to which caregiving is valued can be inferred from the caregivers talk about giving up their own activities and putting lives on hold. This is illustrated by Rose's story about giving up work and becoming a beneficiary in order to support her family while she cares for her mother. In this excerpt Rose discusses how her life has changed now that she relies on a government benefit:

Financially I had just started to get on track and not have to watch every penny when I gave up work... back to no holidays, no little treats, buying second hand clothes, driving a sometimes unwarranted car till I can save up for the repairs, having to say no when my 16 yr old has a school trip...I think the worst part is having to say no everytime my daughter wanted something (Rose, female caregiver for her mother).

In order to care for her mother, Rose has sacrificed things that she, and her daughter, used to be able to do and have. Like Rose, many of the caregivers discussed the adjustments they have made because they have given up a certain lifestyle to become fulltime caregivers. In another example, Sarah says that *she "cashed in a private superannuation scheme 4 years ago and used it to buy a decent car which catered for the special needs of my husband and also my dad"*. In this instance, Sarah's future comfort and financial security is compromised through using the funds saved for her retirement. Caregiving has changed Rose and Sarah's material circumstances, and limited their choices, which

provides support for Bonvin and Orton's (2009) observation that capability is unlikely to be enhanced when there has been a reduction in material well-being. Previous studies have highlighted the issue of women's financial vulnerability in old age. Contributing factors include the hidden costs of providing unpaid informal care and interrupted or prematurely ended employment histories because of caregiving (Hooyman & Kiyak 2011).

Beyond material circumstances, the loss of capabilities affects informal caregivers' quality of life. For example, Margie is unable to maintain or make new friendships because of shared living space. Caring for her mother at home has meant friends have stopped coming to visit and has thwarted a developing relationship with a "man friend", because they "don't get to *spend much time together*". Thus, the capability to care is associated with restrictions, or capability limitations in other dimensions. Nussbaum describes each essential human capability as providing a distinctive dimension, which should not be subject to trade-offs. Choosing one capability over another or compensating for the loss of one by having more of another is an example of tragic choice (Nussbaum, 2011) which precludes human flourishing.

Trading other capabilities in order to care creates a 'pinch' which has the potential to adversely affect caregivers' health and wellbeing. Interventions to support informal caregivers focus on individual compensation, such as benefit payments, counselling services and respite care (Brown & Brown, 2014). However, compensation for lost resources does not necessarily restore diminished capability. Some people refuse or delay asking for support because of the stigma attached to being a beneficiary. For example, Jane waited until her savings ran out before applying for a benefit. Respite care may be refused because the need for help is perceived to be some kind of failure on their part,

“Only reason stepfather surrendered was he himself was admitted to hospital due to stress and now an illness himself...wouldve seen help of any kind as criticism” (Molly, female caregiver for her mother). Respite care appears to address needs for time away from caregiving responsibilities, but can be difficult to organize or not feasible because the care recipient refuses care from a stranger and the emotional attachment precludes passing on the capability to care: *“My own GP suggested a break away, which while the idea was good is not possible. Neither of them want someone else to come in and look after them”* (Pat, female caregiver for her husband and mother). Instead, many caregivers intimated that they would wait until caregiving had ceased before resuming their former activities.

One day my life will go on

Given the often long-term nature and constant demands typical of informal caregiving relationships, caregivers may experience longing for a different kind of life, as Sally’s comment indicates:

As mean as this sounds, I am looking forward to what I call my next life. When I know I have looked after hubby and mum as long as its needed, but when they are gone, I will have My life. Im going to be totally selfish and look after me...it will be very strange to me too, cos all my life I have looked after others. Its what keeps me going some days (female, caring for husband and mother).

Talking about her belief that choosing not to care is not an option, Sally says, “I am looking forward to what I call my next life”. Sally copes with caring by putting her own life on hold.

Many caregivers struggled to manage caregiving alongside other everyday activities. One comment in particular, *“one day my life will go on”* epitomizes the caregivers’ forum postings, suggesting that other activities and caregiving co-exist

uncomfortably. This occurs irrespective of whether the caregiving experience is positive, negative or a combination of both. Attentiveness, responsibility, competence and responsiveness (Tronto, 1993) are all moral principles advanced by care ethicists as providing an admirable and much needed balance in societies that privilege individual achievement and autonomy. Being empathic, anticipating another's needs and putting them ahead of one's own are also valued caring qualities; according to Sally it is "*not natural to put yourself first*". However the caregivers' stories in this study suggest that it is difficult to incorporate a caring ethic into everyday activities, and attend to their own needs at the same time. Many of the caregivers discuss sacrificing or giving up their own plans and dreams. For example, they talk about "*giving up your own life*", "*putting life on hold*", and grieving for a "*potential life lost*" in order to be able to provide the practical care required by the person they are caring for.

The comment "*one day my life will go on*" illustrates the struggle caregivers experience in maintaining their previous 'selves'. The observation that providing care requires bracketing off or putting their 'normal' lives to one side, points to the uneasy co-existence of normal daily activities and caregiving; and highlights the tensions that care ethicists have noted. Expectations that people will live an independent life are part of a culture dominated by neo-liberal ideology, in which lives are understood as individual projects that reflect personal choices and values (Breheny, Stephens, & Spilsbury, 2013; Ferguson, 2001). Dependency is seen as an interference that disrupts these individual projects (Kittay et al., 2005). Thus, the sense of burden expressed by some caregivers reflects a particular socio- historic moment (Mills, 2000) in which the needs of the independent individual are paramount. This creates a tension between the self-focused, independent individual constructed by neo-liberal ideology and those who wish to invest

their time and energy in a caregiving relationship.

In this sense, having the capability to care for dependents “cannot unambiguously be seen as contributing to the well-being of the worker” Robeyns (2003, p.8). Robeyns’ argument may be valid in the context of caregiving as work, however it neglects the complexity associated with the relational aspect of caregiving. The stories from this study suggest that it is not having the capability to care that compromises caregivers’ wellbeing, but rather being unable to combine caregiving with other valued activities once the decision to care has been made. Feminist discussions of the gendered nature of caregiving and the pervasive view that caregiving is women’s work imply that, given the choice, some women would prefer to be doing other things. In contrast, the women, and men, in this study indicate that their first choice is to have the capability to care for someone they love and share a relationship with. Furthermore, choices about the provision of care are not made by autonomous, rational actors. Rather, they are made in a relational context, whereby the wellbeing of the person being cared for is important to the wellbeing of the caregiver. This creates tension between being able to choose what is best for the person being cared for and what is best for the caregiver, which results in the caregiver invariably deciding to forego other valued capabilities. This suggests that informal caregivers require better support to enable their care for others while attending to their own needs, without the level of self-sacrifice that is currently observed.

Conclusion

The CA demands thick descriptions of what people are able to do and be (Sen, 1980); however, this aspect of the approach remains largely underdeveloped, mainly because of the difficulty associated with handling “multiple informational spaces” (Comim, 2005, p.162). The present study demonstrates that a qualitative methodology

offers a valuable solution to this problem. Using the CA provided valuable insight into the minutiae of informal caregivers' daily lives, with Nussbaum's ten central capabilities providing a useful basis for understanding informal caregiving. Asking which capabilities are important for informal caregivers' health generated three main analytic findings: the value of a capability may be noted by its absence; the capabilities are recognized but overlapping; and that the capability to experience emotions is important across all the capabilities.

Important capabilities, such as enjoying good health and having leisure time, were identified because they were lacking in the caregivers' lives. A lack of one capability was most likely associated with at least one other capability, often creating a ripple, or domino effect. For example, being able to care may require giving up employment, leading in turn to financial stress and inhibited leisure activities, which eventually affects the caregiver's sense of wellbeing through social isolation.

Emotions emerged as being strongly implicated in these 'chain reactions'. We found that being able to care for a loved one is a valued capability and that emotional attachment informs the decision to provide care, as well as how care is managed in conjunction with caregivers' own needs. This supports Collins' (2004, p.102) observation that "values are cognitions infused with emotion". Attending to the emotional tensions inherent in a caregiving relationship challenges the perception that providing care for others is a 'natural' activity that is easily incorporated into everyday life (Walker et al., 1995). Rather, the self-sacrifice and self-neglect characteristic of emotionally-invested informal caregiving relationships indicates that the contemporary experience of informal caregiving is an extraordinary activity. If each essential capability is fundamental to health, then enabling the capability to care for others at the

expense of other valued physical, social, and emotional capabilities is unacceptable, and work to support informal caregivers must focus on redressing this imbalance.

Furthermore, the emotions experienced by informal caregivers during the caregiving process are varied and complex and best understood within a wider social location. Understanding these tensions at multiple levels, in terms of personal biographies, relational histories, and wider socio-cultural changes, contributes to a more nuanced understanding of caregiving that moves beyond simplistic notions of care as being either burdensome or rewarding (cf Beach, Schulz, Yee & Jackson, 2000; Hooyma & Kiyak, 2011). The caregivers in our study had committed to providing care for a loved one, but struggled to balance caring for another with contemporary understandings of life as an individual project. These findings have implications for the ways in which we perceive the provision of support for informal caregivers.

Emotional tensions in informal caregiving may be a crucial place to focus institutional support for caregivers. This requires acknowledgment of the interdependent nature of shared bonds and that respite from the 'burden' of care is not always appropriate support. It requires support for the role of caregiving, which could include finding practical ways to strengthen bonds and relationships, not only between caregiver and care recipient, but within families and wider society, including formal health care services and health professionals. This would necessitate working more closely with families to identify their particular needs and strengths, and valuing their knowledge of the person being cared for. Informal caregivers need to be treated as an integral part of the caregiving process, not simply as a convenient adjunct that helps to contain the cost of eldercare.

At the societal level, the tensions between individual self and caregiving roles

suggest that caregivers would benefit from a shift to understanding dependency as including the opportunity to build meaningful relationships, rather than as an intrusion that disrupts individual projects. In terms of Nussbaum's (2007) theory of central capabilities, which she considers are all essential for human flourishing, having the capability to care for others is unlikely to enhance caregivers' wellbeing if it causes the forfeiture of other valued capabilities. The participants in this study describe the emotional complexity of caregiving and the difficulty associated with separating their commitment to, and satisfaction derived from, caring for those they care about, from their own self-development and health. In a society in which caregiving was valued, not as a contribution to the economy, but as a meaningful aspect of daily life, such problems would not arise. Such shifts in focus would mean that family members could experience the choice between caring for a loved one and caring for themselves differently. This would assist those caring informally for older people to have both the capability to care and the opportunity to flourish.

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Link between Chapter Seven and Chapter Eight

Chapters Eight and Nine take the form of two manuscripts, yet to be submitted, which relate to Study Two. Chapter Eight describes the method and shares the methodological insights gained from using a mixed-method approach in qualitative research. Chapter Nine describes the narrative analysis of the Study Two data and presents the results from the study.

At the completion of Study One, a Summary of Results was sent to all of the organisations that had helped with recruitment of participants. The summary included information about a second study and provided contact details inviting caregivers to contact me if they wished to participate. At this stage six caregivers were recruited, however two withdrew very soon afterwards because their caregiving responsibilities increased and they felt unable to commit to the study. Two more participants joined the study after it began, having heard about it through community contacts, making the final total of six. The context for care was varied, as the following biographical details, which use pseudonyms, illustrate:

Pollyanna, aged 66, was caring for her spouse **Bob**, who was morbidly obese and suffers from co-morbidities such as heart disease and diabetes. Pollyanna took early retirement to become a fulltime caregiver, although she said her health was deteriorating anyway, so retirement was a decision that benefited both.

Ciara, aged 63, was caring for her father **Errol**, who had a heart condition and had suffered a series of strokes. Ciara moved into her father's house to care for him and continued to work as a self-employed consultant from home, although her job involved some travel and time away from home, which she had to manage.

Emily, aged 84, was caring for her spouse **Roger**, who was a stroke survivor. He was in

residential care at the time of the study, having gone there while Emily was in hospital and then refused to come home on a permanent basis. Emily was working towards bring him home as she could not afford to pay for his care and complicated family finances meant he was not eligible for a government subsidy. Emily had continued to work while providing care for her spouse, until her retirement.

Allan, aged 63, was caring for his spouse **Anne**, who had a rare terminal illness. Allan sold his business in order to provide fulltime care.

Ian did not provide his age. He was caring for his mother who had Alzheimer's Disease. He was not employed, although his wife was working.

Doug, aged 66, was caring for his mother, who had multiple co-morbidities. Doug was retired and the only participant not residing with the person being cared for.

The participants' situations are diverse, although there are some similarities, such as finding it difficult to maintain employment while caregiving. No other demographic data was collected as it was not my intention to analyse the data according to ethnicity, education, or socio-economic status.

The first study had highlighted that caregiving is a social relationship and that caregivers' emotions influence their decision making and the sacrifices they make. The second study aimed to expand on these findings by undertaking a focused exploration of the role of emotions in informal caregivers' everyday lives. Two main criticisms of caregiver research are the extensive use of cross-sectional and retrospective designs. To address this, the present study used a prospective design, aiming to involve each participant for a six-week period. Additionally, a prospective design provided the opportunity to explore the day-to-day minutiae and travails of caregiving, which I hoped would fruitfully portray their everyday

interactions and decision-making.

The decision to run the study for six weeks was somewhat arbitrary; however, I felt that this would provide sufficient time to gain insight into the caregivers' lives without being overly intrusive or onerous. Confining the data collection to six participants was also somewhat arbitrary. I did not aim to recruit a prescribed number of participants into the study, but after collecting information from the six participants I felt that there was sufficient breadth and depth in the data to warrant stopping the data collection at that point.

The participatory principles that informed Study One were carried over into Study Two, in that the participants were able to choose how they wished to contribute to the study, albeit from options suggested by me. The following manuscript describes the use of a solicited diary/interview method for data collection, which was chosen by four of the participants. Of the remaining two participants, one chose to be interviewed by telephone over a period of several months, and the sixth participant asked if he could take part in the study, but was only prepared to commit to one interview. Although this method of data collection was not what I had planned, I chose to go ahead with the interview and have included the data in the results as it resonates with the findings of the other five participants.

Chapter Eight: Study Two - Method

Horrell, B., Stephens, C., & Breheny, M. Informal caregiving for older people : insights from using a diary/interview methodology. Manuscript to be submitted.

Abstract

Background: In this paper we share the methodological insights gained from using a mixed-method approach in a qualitative study of informal caregiving. The study incorporated participatory principles in so far as participants chose their own method of keeping a solicited diary, which provided the focus for regular, subsequent interviews, during which the participants helped to co-analyse their own data from the diaries. **Aim:** To better understand how informal caregivers experience emotions in their everyday lives. **Method:** Four participants, from different backgrounds, completed up to six telephone interviews based on their diary entries. Participants were recruited over a seven month period in 2013. **Results:** The data were analysed using narrative analysis which provided a more nuanced appreciation of the role that emotions play in caregivers' attunement to the needs of the older people being cared for. **Conclusion:** Overall, we found that the solicited diary/interview method offered benefits for the participants, while providing the researchers with a worthwhile option for gathering qualitative data that complemented the more customary interview approach and produced rich, reflective and insightful information that might otherwise have been passed over.

Keywords: Solicited diaries; self-directed photography; visual diary; diary/interview; informal caregiving

Informal caregiving for older people : insights from using a diary/interview methodology

Introduction

Informal caregivers are mostly unpaid relatives and friends of someone who depends upon help to continue living in their community. The negative health consequences of providing informal care have been well documented, however the focus on adverse outcomes has been contested (e.g. Nolan, Grant & Keady, 1996). Brown and Brown (2014) argue that negative findings often relate to small, retrospective studies, citing larger cross-sectional studies and prospective studies that report beneficial health and well-being outcomes for caregivers. Prospective, qualitative studies have the potential to facilitate a more nuanced understanding of lived experience, and this informed the design of the present study, which was the second of two studies concerned with the health of informal caregivers for older people. Having identified, in the first study, that emotions are implicated in informal caregivers' decision-making (Authors, in press), we focussed a second, prospective study on feelings in the context of caregivers' ongoing relationships with the people being cared for. Over an extended timeframe we used solicited diaries in conjunction with repeated, sequential interviews to gain a deeper understanding of the participants' choices and interactions in their everyday lives as caregivers for older people. In this paper we share the methodological insights gained from using this mixed method approach. The substantive study results are reported elsewhere (Authors, forthcoming).

Diaries have a long multidisciplinary research history, dating back as far as the early 1900s (Iida et al., 2012), and have been used in psychology, sociology, health care, market research and information technology (Toms & Duff, 2002). Qualitative diary research has been utilized as a relevant method to capture the practices and experiences of routine

behaviours in everyday life (Elliott, 1997; Kenten, 2010), including the health and behaviour of older adults (Jacelon & Imperio, 2005; Johnson & Bytheway, 2001). Diaries may be unsolicited private journals where the diarist's entries are intended for their eyes only, which raises ethical questions about their use in research (Meth, 2003), or they may be solicited for research purposes. In this case, diarists are aware that they are writing for a specific purpose and that their entries will be read and analysed by a researcher.

The first stage in the solicited diary/interview process is completion of a solicited diary that enables research participants to actively contribute, or collaborate with a researcher, in both recording and reflecting upon their experiences (Elliot, 1997). Solicited diaries may be structured, using survey style formats with tick-boxes, and time-use logs; or unstructured, using open formats where the diarist has more control over what, when and how much to record. Some studies utilise a combination of both styles of diary. Solicited diaries have been most commonly used within health research to gather data in a convenient and relatively unobtrusive manner (Lee, 2000), for extended periods of time (e.g. Furness & Garrud, 2010; Harvey, 2011). Research with marginalized groups features strongly; including people with disabilities (Kenten, 2010), older people (Milligan, Bingley, & Gattrell, 2005), and the caregivers of people with dementia (Valimaki, Vehviläinen, & Pietila, 2007).

Solicited diaries in health research commonly use time-use methods to record and verify daily activities and bodily practices (Thomas et al, 2011; Stapleton & Doyle, 2013). However, open solicited diaries have also been used successfully in qualitative research to record and reflect upon personal and emotional experiences, behaviours and events (e.g., Malacrida, 2007; Meth, 2003; Milligan, Bingley, & Gattrell, 2005; Thomas, 2007). Solicited narrative diaries have potential as a detailed source of data that reflect the diarist's values and priorities as well as what the researcher may consider relevant (Symon, 2004). Because the

content is negotiated between researcher and participant it is likely to reflect the researcher's interest, but the participants have final authorial control over the diary content.

Being able to choose what to disclose in an open diary modifies the power dynamics that inevitably arise in an interview situation (Couldry & Markham, 2007). Additionally, participants are more likely to become engaged in the research process (Chapman, 2006). Enabling participants to identify what is important to them can be empowering, and also alerts the researcher to the participants' priorities (Meth, 2003), which are subsequently followed up within an interview. The participatory benefits of solicited diaries informed our decision to use this method in the current study.

Compared to other data collection methods, solicited diaries have a number of advantages. Because experiences are recorded as they happen, they provide an alternative to the traditional interview method where events may be easily forgotten or overlooked (Corti, 1993). Retrospective interviews rely on memory, tending to generate less contextual and more idealized biographical narratives and general opinions (Alaszewski, 2006). Diaries may be used to record events contemporaneously and over time (Elliot, 1997) and being able to follow participants' feelings and behaviours over an extended timeframe is likely to provide a more considered appreciation of the embodied and emotional complexities of everyday life (Meth, 2003). Using this method to enhance recall (Symon, 2004), is particularly helpful when conducting research with older people (Johnson & Bytheway, 2001).

Secondly, diaries can minimise problems associated with collecting sensitive information in an interview (Meth, 2003). For example, diarists are more likely to include emotional data because entries are written closer to the time of the event, and written in a private arena, without the researcher present. The flexibility of being able to choose when

and how much to write (Elliot, 1997) is another benefit of keeping an unstructured diary, which is an important consideration for people like informal caregivers who lead busy lives that are often punctuated by unpredictable events. In this sense, solicited diaries “create a series of first-hand images” of daily life (Johnson & Bytheway, 2001, p.203). Finally, the reflective nature of keeping a diary provides a rich source of information about the taken-for-granted aspects of everyday life (Koopman-Boyden & Richardson, 2013) upon which to base supplementary interview data (Lewis, 2006).

While diaries have significant benefits as a data source for social researchers, they do have their limitations. Keeping a diary requires commitment that may be difficult to maintain; as a result diary content may decrease as the study progresses and participant retention may be problematic (Toms & Duff, 2002). Secondly, because participants choose what they enter in an open diary the content may be highly variable, less detailed, or differ from the researcher’s expectations (Bijoux & Meyers, 2006). Finally, being able to keep a diary requires having the necessary skills. For example, writing may be difficult for older people because of deteriorating health and eyesight problems (Milligan et al., 2005). On the other hand, deciphering handwritten material may be problematic and time consuming for the researcher (Johnson & Bytheway, 2001). One way of overcoming this is to offer participants the opportunity to select the method most suitable for them. Handwritten or typed text, audio recordings or visual diaries using self-directed photography all represent potential options for recording everyday experience.

Cheaper and more user-friendly digital technology has advanced the use of photography in visual diaries to elicit information in qualitative studies (Harrison, 2002). Self-directed photography often combines photography with writing, and has been most commonly utilized to enable the narratives of people whose voices are often marginalized

(Mizock, 2014). Self-directed photography may be used to overcome literacy and language difficulties. Following guidelines that are more or less structured, participants are encouraged to photograph aspects of their lives that reflect the researcher's phenomenon of interest. At the same time, the photos are assumed to represent the photographer's priorities and what they want to communicate. It is the participants who select the images that will be incorporated into the research, especially when the photos provide the focus for follow-up interviews or focus groups (Bijoux & Meyers, 2006). In this way, self-directed photography minimises the researcher's 'voice' and allows research participants the opportunity to construct accounts of their lives in their own terms.

Solicited textual and visual diaries are commonly employed as a complement to other qualitative methods of data collection, such as in-depth interviews. Combining photos with text and follow-up interviews in the photo-diary: diary interview method (Latham, 2003; Schulze, 2012) can be used to elicit further information, providing a more complex and nuanced picture of lived experience and facilitating access to interpretations that might otherwise be inaccessible to researchers. This mixed method approach creates a "methodological strategy that adds rigour, breadth, complexity, richness, depth and creativity to the research" (Bijoux & Myers, 2006, p. 48). Reviewing diaries and photographs within an interview situation is a collaborative form of analysis where focused questioning by the interviewer and elaboration by the participant facilitates deeper insight into the meaning of the primary data for the participant (Aitken & Wingate, 1993). In this way, "participants actively negotiate the details of the photos and diaries, revealing their identities to themselves as well as to the interviewer" (Gibson, 2010, p.387).

The diary-interview method may be conceptualised as an alternative to participant observation (Zimmerman & Wieder, 1977), providing a valuable way of accessing hidden or

“muted” information (Elliot, 1997). This includes topics that the researcher may not be aware of, sensitive issues that are difficult to talk about face-to-face, or the taken-for-granted aspects of everyday life, such as the provision of informal care. The diary-interview method encourages reflexivity on the part of both participant and researcher, particularly when writing and talking about emotions (Spowart, 2014).

Interviews may be open, following the priorities of the person interviewed, but focused through the researcher’s lens of interest, or they may be more structured, with set questions asked in a particular order (Gergen, 2010). Qualitative researchers are most likely to use an open, or semi-structured format. This type of in-depth interviewing facilitates questioning about deeply significant and personal issues (Bergman & Hallberg, 2005), and it is possible that over time, the position of the respondent may shift on a specific topic as the person feels more trusting and at ease with the researcher. The researcher’s position may also change as a result of the participant’s input (Flick, 2000; Reinharz & Chase, 2002). Alternatively, respondents may endeavour to present consistent views and only those that they feel are socially acceptable in an interview situation (Gergen & Davis, 2003).

Having identified, in the first study, that emotions are implicated in informal caregivers’ decision-making (Horrell, Stephens & Breheny, 2015), we focused this second, prospective study on feelings. We invited caregivers to diarise their ongoing daily activities as informal caregivers, and asked them to focus particularly on the emotional aspects of their role. Our previous study had highlighted tensions and ambivalence associated with informal caregiving as an ongoing process. We were interested in the contextual background for this complexity and aimed to collect data that reflected the dynamic, interactive nature of caregiving relationships.

The diary contents provided a springboard for further discussion and elaboration in subsequent regular in-depth interviews with the researcher. We felt this approach matched to our aim of better understanding how emotions affect the wellbeing of informal carers for older people. In the next section we outline the ways in which these methods were combined in practice.

Method

The Capability Approach (Nussbaum, 2007; Sen, 1980) provided the theoretical framework for the present study. This approach conceptualises wellbeing in terms of having the capability to achieve valued activities. We offered the participants the option to use the diary/interview method as a means to enhance understanding of the association between emotions and the things that informal caregivers value, based on increasing recognition that the open, reflective format of solicited diaries highlights participants' priorities and understandings about what are often taken for granted issues (Elliott, 1997; Milligan, Bingley, & Gatrell, 2005; Worth, 2009), and because diaries have the potential to allow researchers access to emotional contexts not normally available to them (Elliott 1997; Meth 2003).

Recruitment

Although six informal caregivers from New Zealand took part in the original study, only four chose the diary/interview method, upon which this paper is based. Three were recruited immediately following the dissemination of results from our first study, via the media and various organisations that had supported that study. The fourth participant volunteered later, after having heard about the study from someone in her community. Another participant had given consent and received her diary, but withdrew from the study before making any entries because of escalating caregiving commitments.

Participants and Procedure

The participants were aged between 63 and 84; three (two females and one male) were caring for a spouse and three (two males and one female) for a parent. The care recipients' ages ranged from 64 to 92, with illnesses including heart disease, diabetes, stroke, morbid obesity, Alzheimer's disease and a rare terminal illness. After an initial screening conversation, which ascertained that potential participants met the eligibility criteria of caring informally for an older person in the community, and described the range of methods for keeping a diary, participants were sent further information, based on their choice of data collection. The first author (BH), who was also the main researcher and interviewer, suggested keeping a written or audio diary, taking photos, poetry and song-writing as potential methods for relating their experiences, but participants were invited to choose their own method of diarising their daily activities and feelings. Suggesting these different options was intended to extend the possibility for caregivers, who might otherwise have felt excluded by limited literacy skills, to participate. All interviews were conducted by telephone.

This flexibility afforded the participants responsibility for, and control over, data generation in that they could choose when, what and how to record their ongoing experience of caregiving. It also required flexibility from the researcher in order to accommodate the participants' preferences. Various methods for keeping a diary were chosen, and included a hand-written journal, a weekly word processor document, emails, and a combination of emails and photographs with accompanying text sent via Facebook. These methods evolved during the data collection phase. A journal was supplied to those who chose to write in traditional diary form. The journals contained blank pages and resembled a proper diary in that they were A5 in size and had a ribbon page-divider. The unstructured nature of the journals meant that participants could choose how much to write. The only guidelines

provided were an explanation of the background to the research and that this study was focusing on feelings associated with caregiving. Participants were invited to write as much or as little as they liked. The journals were spiral bound, to enable the participants to easily scan and email the pages to the researcher, and the pages were perforated so they could be removed and posted to the researcher if desired. One participant supplemented her diary with retrospective excerpts from her own private diary, dating back to when her spouse first needed care and emailed this to the researcher as a word processor document at the end of each week. Two participants recorded their thoughts and activities in the diary, but chose to type up the entries at the end of the week and email them rather than scanning or posting the pages. Diaries with attractive covers were chosen in anticipation of them being kept by the participants as a keepsake.

The optimal time for keeping a research diary is a matter for debate and varies between studies (Morrison, 2012). Jacelon and Imperio (2005) suggest that 1–2 weeks is an appropriate length of time, however studies vary from anywhere between 3 days (Myers, 2010) to 6 weeks (Meth, 2003) or even longer. In this study, we asked the participants to keep a diary for 6 weeks. Being aware of informal caregivers' existing time constraints we did not want to place unnecessary demands on their time, yet we aimed to collect data that reflected the dynamic, interactive nature of caregiving relationships. We anticipated that emotions would fluctuate over time and were interested in the contextual background for this complexity.

The information gathered provided a starting point for regular sequential in-depth interviews between BH and each participant. BH received the participants' diary extracts and photographs before each interview, enabling her to compose individualised questions or prompts for the telephone interview, which was recorded and transcribed prior to analysis.

Each participant contributed up to six interviews, for a combined total of 22 interviews. Interview times ranged from 28 minutes to 1 hour 20 minutes. Originally an interview each week for six weeks was planned, however, caregiving commitments meant rescheduling for some participants, so each participant's involvement with the study varied from seven weeks up to several months. Only three of the participants completed the full six interviews. In all, we ended the study with almost 21 hours of recorded interviews. These interviews were based on one handwritten diary of over 7000 words, two email diaries of around 5500 words each and one self-directed photo/email diary containing around 50 photographs and 1220 words. Photographs were received via a private Facebook group, set up by the researcher. Data collection took place between March and September 2013.

Each participant signed a consent form that related to the specific method chosen for the study. Additionally, the participant who chose self-directed photography was asked to obtain consent from the person being cared for before they were included in any photographs. This participant was advised that the photographs were for stimulating discussion in the interviews only, and that no images they had taken would be published. The participants chose their own pseudonym to be used in any future publications. These procedures were approved by the University Human Ethics Committee

Analysis

The participants' diaries and photographs provided access to the contexts and processes associated with caregiving, with the follow-up interviews enabling clarification and deeper understanding (Bijoux and Myers 2006; Elliott 1997; Latham 2003). The analytical process began after transcription of the interviews. The diary text was not specifically included in the analysis, because the intention was to use this information to aid recall and to prompt discussion in the telephone interviews, where much of the information was repeated.

However, revisiting the diary entries could form the basis for analysis in the future.

BH began the analysis by reading through the transcripts, with occasional reference back to the diaries and photographs, to identify the participants' "personal stories" (Murray, 2000). This narrative approach to analysis was chosen as a means to understand the complexity of caregiving as a relational activity embedded within a social context. Narratives often take the form of stories people tell to make sense of their lives (Gergen, 2010) and the narratives identified were understood to be co-produced between the participants and the interviewer. The results of this analysis are reported elsewhere (Horrell, Stephens & Breheny, forthcoming). All names used in this paper are pseudonyms.

“A time for me to reflect on my life as a carer”

The participants' diaries and photographs provided a wealth of qualitative data, illustrating the complex and multidimensional quality of caregivers' experiences and providing the basis for follow-up interviews. The four participants who kept diaries approached the task in different ways, which resulted in different styles of data collection and the presentation of different types of data. The following section describes each participant's approach to keeping a solicited written or visual diary and examines the methodological implications for the subsequent in-depth interviews.

Written diary

Three of the participants chose to keep a journal-style diary, albeit with different methods of presentation and writing styles. Välimäki (2007) has identified four types of diary: meagre, descriptive, reporting and reflective. In our study we found that each diarist used a combination of these styles, although one predominated for each participant. None of the participants produced meagre diaries. Below we describe the different types of diary submitted by each participant.

Ciara

Ciara, 63, single, lived with her elderly father. Her diary entries demonstrated a high level of self-reflexivity and she generously shared her experiences and thoughts in great detail. Her first entry read, “*Pleased to receive diary as it will [be] a time for me to reflect on my life as a carer*”. This reflexivity carried over into her interviews, where she was happy to co-analyse her entries and responses to events in her daily life. Ciara’s entries were regular, long, detailed and reflective. She did not produce an entry every day, but did send weekly updates, apart from when she was busy with other commitments and arranged to send what she could, when she could. This stretched the data collection time out to seven and a half weeks. Ciara had filled her 70 page diary by Week 5, supplementing the final weeks’ record with her own paper. The length of Ciara’s entries varied from week to week, ranging from 5 pages to 32 pages in Week 5 (which were written during what Ciara described as, “*A very difficult week*”). Ciara’s contributions remained closest to the researchers’ focus on feelings. She often started her entries with “*I feel...*” or “*I felt*” as she disclosed feelings of betrayal, guilt, anger and loneliness, as well as more positive feelings of empathy, compassion and happiness.

Although acknowledging that “*it is good to see this written as it helps me realise the amount of stuff I do*”, at times Ciara questioned what she had written. For example, in one entry under the heading “*Random thoughts*” she wrote, “*reflecting on my own life at the moment it is a sort of desperate improvisation*”. The entry continued with comments about “*conflicting elements*”, “*multiple commitments*” and the desire for “*a simpler life*”. She concluded with the realisation that it is impossible to integrate her own commitments with being a carer. However, in the follow-up interview the first thing she said was

*I'm just looking back through the... um, I think that last page I sent to you, the random thoughts was interesting for me. Um, *pause* I mean I've said there, you know, um, this idea of the desperate improvisation, and you know, sometimes it's not desperate. I don't want you to think it's um, I'm feeling desperate all the time ...*

On another occasion Ciara reflected on how the negative tone in some of her entries made her feel like she was being petty and complaining about small things, which was an aspect of herself she did not like.

Being able to re-read what she had previously written gave Ciara the chance to think about her spontaneous comments and qualify or correct what she had written in the ensuing interview. Had Ciara not had this opportunity, the fluctuations in her cognitions and emotions may have remained invisible to the interviewer. At one point Ciara wrote "*If emotions were different colours I would've been a bloody rainbow*". As Harvey (2011) points out in her study of intimate everyday experiences, this form of reflection opens a window into the complex, and at times ambivalent feelings experienced in daily lives. In one-off interview these moments, which provide valuable insight, may be forgotten, overlooked, or smoothed over.

Allan

Allan, aged 63, was a caregiver for a spouse with a rare terminal illness. Nine years ago he had sold his business to be a fulltime caregiver for his wife Anne. Allan's diary was typed (from handwritten entries) and regularly emailed to the researcher. Seven lengthy emails were received in the first three weeks. However, flexibility from the researcher was needed to accommodate Anne's hospital admissions and a very rare trip away for Allan. For Allan to be able to take time off meant their daughter had to take an unpaid holiday and travel

from Australia to care for her mother. Data collection time for Allan extended over a 12 week period, due to the interruptions, however only three interviews were completed.

Allan structured his diary quite differently to the other participants. Focusing on descriptions of daily activities, he adopted a time-use reporting style, recording the date and time of day for his entries. For example, a typical entry read

6am. Woke up and gave Anne her medication, listened to the radio for a while 6.45am had shower etc. Checked and fed my [fish] it takes about an hour as im breeding so there are quite a few i would go mad without them. 8.30am. Checked Anne still asleep so i made myself some breakfast, read paper, checked emails etc, no emails. 10am. Caregivers arrived to shower Anne, i popped down the road for a coffee, came back at 10.45 only 1 caregiver arrived what a joke. Made and fed Anne some porridge, change in weather and she likes it, easy to eat...

In this way, Allan mainly described his daily routines, and spent less time reflecting on his feelings, so the interviewer had to 'read between the lines' to prepare for the interviews. Nevertheless these comments did provide useful data for follow-up discussion. Although Allan's entries were mainly descriptive, at times they were also insightful, especially when his writing changed to a 'stream of consciousness' style

Sorry rabiting a bit on here. I dont know whats wrong with me today its 1pm the resbite lady is back and ive done nothing, better get some soup out the freezer for annes lunch, i wish somebody would come in and take over for a few days. Im off out for a couple of hours, running out of places to go, im having a i cant be fucked day, i suppose you have to have them sometimes.

This kind of entry provided valuable insight into Allan's life as a caregiver, which the interviewer tried to expand upon in the interviews. However, when the interviewer tried to tease out Allan's feelings his responses were often short and matter of fact, or less articulate than his written entries, so the conversation was often stilted and did not flow. For example, following up on an entry about a miscommunication with the Ministry of Health over respite care, the researcher asked

R. *How did that make you feel?*

P. *Like a piece of shit. *pause* that's when I abused her [the respite coordinator] a bit. I just couldn't believe it.*

R. *Cause that's really important to you, the respite care isn't it?*

P. *Yeah, I couldn't do it without it. You just can't do it. You know, it's um, it's a weird thing, I don't know. I mean when I, I made sure everything was right, even when they stuff up all the time, I mean we've had so many problems with them it's not even... you know...*

Fortunately using the diary entries as a contextual adjunct to the interviews enabled the researcher to piece together a vivid picture of Allan's lived experience, which facilitated a much more nuanced analysis than if she had had to rely solely on interview data. In general, the participants were more communicative in their diaries, compared to their interviews, with the diaries providing some of the richest data in the study. Like Ciara, Allan also felt the need to qualify his journal entries, ending his first email with the following statement, "*Irrespective of the thoughts in my journal i do not in anyway resent my decision to keep Anne at home*".

This comment highlighted that the story told of the day-to-day trials and tribulations of informal caregiving does not undermine the broader project of caregiving that the caregivers are focused on, which is something that may not become apparent in the context of a one-off interview.

Emily

Emily, aged 84, had been caring for her husband, through a series of strokes, for 13 years. He had recently spent time in a residential care facility while Emily was in hospital and at the time of the study was sharing his time between the care facility and home. He said he did not want to move back home fulltime, but Emily said he would have to as their financial situation was complicated and she could not afford to keep him there. She said he did not ‘need’ to be there. Emily said she initially felt “*peculiar*” about his decision, but had come to enjoy her freedom and independence and “*surprisingly*” she liked living on her own. Emily had always kept a diary, so she would email two documents each week; one contained excerpts from a diary dating back to 1990 when Roger had his first stroke, and the other was a typed copy of the solicited diary she was keeping for the study. Emily’s style of writing was a combination of description and reflexivity, although her entries did not display the same level of reflexivity as Ciara’s entries.

Near the beginning of the study Emily mentioned that keeping the research diary was good for her

P. *You know, writing all this down, you’ve done me a great turn you know.*

R. *Oh really?*

P. *You really have, because I’ve seen it, I see it from a different perspective when I actually tabulate everything that’s happening to me, you know...*

In Emily's case it was very useful to have the diary entries to refer back to as she had struggled with recall and finding the right words since her own stroke the previous year. She tended to get confused about the order of things that had happened in the past and was easily side tracked in her thought processes as the excerpt below illustrates

R. Right, so he had further strokes then?

*P. Oh yes, he's had two more. But he recovered pretty well from the first one because he could drive from 1990 on... I don't know whether I've got that actually accurate... yeah I think I might've. Oh dear... *pause* that was the 1990... *pause* oh he tells me today that he got to see his uh, optometrist, he says he can't really see properly. Short range, he can see long. *laughs* oh dear, oh dear. *pause* Yes, it was, you know, as I've said in hindsight I realise that his stroke was quite minor, well it was to what's happened subsequently.*

This observation stands in stark contrast to what Emily had recorded in her diary in 1990 when Roger suffered his first stroke. Then, she talks about stopping to buy tissues on the way home from the hospital because they could not stop crying, and not being able to bear telling anyone what had happened. The stroke had come as a huge shock and was an intensely emotional time for both Roger and Emily. Time, however has softened that memory and Emily now recalls the severity of the event from a different perspective. An obvious benefit of keeping a research diary is the immediacy of recording an experience, which increases the likelihood of more accurate recall. Having the serendipitous access to this participant's earlier diaries highlights that, compared to an interview that looks back at life events, where, events are likely to be retrospectively reframed by subsequent life events, having access to a diary tells a different story of life in the moment. Being able to compare

the two different forms of narrative in the analytical phase illustrate the performative aspect of narratives as well as the notion that multiple stories are able to be told, especially when co-constructed with another.

Emily's diary entries illustrated the value of reflective journaling for research purposes. Whereas she struggled at times to think quickly in response to the interviewer's questions and formulate an eloquent response, Emily was able to write in her diary at her leisure, which allowed time for reflection. Emily often woke in the early hours of the morning and used this time to update her diary. In comparison to her interview responses, these entries were more detailed and carefully formulated, which is illustrated by comparing the following extract with the one above.

What I have found really difficult since my stroke has been my ongoing habitual role as Roger's carer and to balance that with my need for considerable help to recover my own health. From being able to cope with most challenges I now find I have to rely on others and accept help instead of giving it. Losses like selling our car, anxiety about my retirement fund dwindling, worry about my own health status and side effects of medication, not always being able to rely on my memory have all required adjustments in life style.

This excerpt highlights that keeping a diary gives participants more control over how and what they want to say, which fits well with a participatory approach (Worth, 2009).

Visual diary

Pollyanna

Pollyanna was the only participant to choose self-directed photography as a method for documenting her caregiving activities. Explanatory text and emails accompanied the

photographs. Pollyanna was 66 years old and caring for her morbidly obese spouse Bob who struggled with multiple co-morbidities, including heart disease and Type II diabetes.

Although Pollyanna was the primary caregiver, she also had health issues of her own and was hospitalised during the course of the study.

Initially Pollyanna was enthusiastic about sending photos for the study. The photos were a combination of 'selfies', photos taken by Pollyanna of everyday places and objects, and photos taken of Pollyanna by others. However at times she did not send photos relating to that week; she had either not had time, or on one occasion had left her camera at a family member's house and had to wait for it to be returned. Instead, she sent historical photographs of past events, including one of an enjoyable day out when Bob was able to walk a reasonable distance unaided. These photos provided a more longitudinal view of Pollyanna's life as well as further material that acted as prompts in the subsequent interviews.

Photo diaries are particularly useful for enabling the researcher to visually locate in the participants' in their own setting (Bartlett, 2012). Pollyanna prefaced one set of photos depicting her first walk since her operation with the words "You can walk the short distance with us". Her spouse Bob took most of the photos, following Pollyanna on his mobility scooter. The photos began with a view of Pollyanna walking out of the lounge, and ended with a final photo of Pollyanna asleep in her chair, with the caption "*phew exhausted.... my ambition was greater than my stamina*". This was a compelling group of photos that showed both the interior of Pollyanna's home and her surrounding neighbourhood, enabling the researcher to visualize the environment for Pollyanna's caregiving. However, on another level the photos provided a metaphor for Pollyanna and Bob's life together, highlighting their shared caregiving journey. It became evident over the course of six interviews that although they have their ups and downs, Pollyanna and Bob are deeply committed to their marriage

and caring for each other. Although Bob is limited in what he can do for Pollyanna, he is concerned about her wellbeing. Pollyanna commented that he followed her on his mobility scooter because *“He always thinks if I collapse or something he’ll be able to pick me up and bring me back, but the scooter wouldn’t carry both of us”*.

Pollyanna’s sense of humour shone through in the photographs she chose to include, and in her interviews. This was illustrated in the two photos depicting a meal that Bob had prepared while Pollyanna was out collecting for a national charity. Pollyanna placed the photos side by side, showing a large plate of salad for morbidly obese Bob, whereas Pollyanna’s meal of mashed egg on toast looked less healthy but was all she could eat due to her ongoing digestive and bowel problems.

Many photos portrayed the daily activities Pollyanna enjoyed. In one photograph Bob had photographed Pollyanna, sitting in her chair knitting, surrounded by everything she needed for the day, within easy reach. This included her laptop, which was her lifeline to the outside world, both as a means of social support from various Internet chat groups as well as a way that Pollyanna could support others which she said she *“needs”* to do. Additionally Pollyanna photographed important objects. For example, she included a photo of the reclining chair that had been manufactured especially to hold Bob’s weight, side by side with photos of an oversized chair Bob had to use while his recliner was being repaired and a normal kitchen chair used by Pollyanna. The significance of these common household objects, which Pollyanna referred to as the *“Goldilocks and the three bears chairs”* was revealed in the ensuing interview when Pollyanna discussed the strain on their relationship caused by Bob not being able to use his recliner. She said *“so the chair affected us quite a lot um, for both of us because it left him unsettled and restless. It left him, taking himself off you know, and lying on the bed”*. The only place where Bob could be comfortable, apart from his

recliner, is in bed, which meant that Pollyanna could not sit beside him to keep him company, and she hated him to feel isolated. Pollyanna spends much of her day sitting beside Bob, knitting or using her laptop, not necessarily talking or sharing activities, but just being together.

The photos of Pollyanna's everyday activities allowed the researcher to observe, by proxy, what was important to Pollyanna, providing rich, contextual detail about her environment, her hobbies and the important people in her life. This amount of detail, which would have been inaccessible in a one-off interview, provided a vivid backdrop for the subsequent interviews between Pollyanna and the interviewer, and enriched their co-analysis of Pollyanna's life as a caregiver.

Diary-Interview method

The study combined solicited diaries and self-directed photography with follow-up telephone interviews in a mixed method approach. The interviews were incorporated as a way of enabling the researcher to clarify information and encourage the participants to provide more detail about interesting themes arising from their diaries or photographs (Bijoux and Myers 2006; Latham 2003). One of the benefits of conducting telephone interviews is the degree of anonymity that enables a freedom of expression compared to face-to-face interviews (Opdenakker, 2006). This type of interview, in conjunction with solicited diaries has the potential to generate even richer insights into everyday life. However, despite having received reflective and insightful diary entries from the participants it was at times challenging to draw them into conversations with the same depth of focused information. Allan for example, often limited his responses to just a few words or deflected questions, whereas Emily and Pollyanna would talk at length about events in their daily lives that were only tangentially related to caregiving. While this may have been a reflection of the

researcher's interviewing ability, in these instances it was good to have the diary extracts to refer back to, in order to re-focus the interview. At the same time, these 'asides' often produced interesting contextual data that enhanced the analysis and highlighted the benefits of enabling participants to introduce their own perspectives and concerns into the research..

In the following excerpt Emily was prompted by the interviewer to elaborate on her use of the word compassion, the discussion did not go well and resulted in Emily expressing frustration that she could not answer the questions. The conversation began with the interviewer asking Emily why she had used the word compassion in relation to caring. Emily responded by talking about how she was pleased that the meaning of compassion had not changed, as opposed to words like 'gay', but could not explain what it meant to her. The interviewer tried to prompt her by saying

R. Do you think it's one of the main reasons why you care for somebody, because you feel...?

P. Yeah, I do. I think it is. Um, compassion... oh, I suppose there's a dictionary thing of it. Right, oh, I'm no use at this, I can't think.

R. No, that's alright, I just was interested that you'd used that word to describe how people care, like, what you've put: 'A carer's effort, understanding and compassion enables a person with ill health, disability or mental illness to live with dignity and participate socially.' And I just thought that was a wonderful sentence...

This exchange highlights the difference between a response that has been carefully thought out at by the participant, at her leisure, and the information gained from direct questioning requiring an immediate answer. Because the diary/interview approach allows participants some control over the pace of data collection (Bartlett, 2012) this method has potential for

researchers interviewing older people who may feel pressured to respond in a one-off interview.

Strengths and weaknesses of the diary/interview method

Building relationships

One of the benefits of the diary/interview method is relationship building between the researcher and the participants over time, which may enhance trust and rapport leading to the disclosure of sensitive information. Additionally as Meth (2003) notes, the nature of journaling over time, with breaks between entries, showcases changing thought processes and reactions, which in this study highlighted the ambivalent nature of caregiving. One-off interviews may be less likely to capture this complexity.

While the extended time frame may facilitate the building of trust and rapport with the participants, it does have its drawbacks. The longitudinal nature of this study combined with the disclosure of sensitive information presented a challenge to the first author in terms of maintaining detached objectivity or emotional neutrality (Fitzpatrick, 2015). During the study, she felt uneasy about the participants contributing to a one-way relationship. She was mindful that she was expecting the participants to share their lives and discuss their emotions with her, yet she was sharing little about herself. At the end of the study, she also felt somewhat awkward about terminating the 'relationship'. It was therefore reassuring to receive participants' feedback stating that they had enjoyed the process, finding it worthwhile and enlightening.

Reflexivity

A strength of the diary /interview method was the researcher receiving the participants' diary extracts and photographs prior to each interview, thus allowing her time to

reflect upon the data and personalise the questions for each participant. Similarly, the participants often took the opportunity to re-read what they had written before the interview and came prepared to discuss or even contradict what they had written. Previous studies have indicated that participants benefit from the reflective nature of personal diaries (e.g. Bartlett, 2012). The final comments from the participants in this study appear to support this. Emily remarked that the study had done her a “great favour” by allowing her to reflect on her life as a caregiver. Similarly, at the end of her final diary entry Ciara thanked the interviewer for the introspective nature of the interviews, concluding

I have really enjoyed the process... I think I will continue to find time for the journal. It's very helpful – forces me to take time to reflect and I think by doing that I review how I do this job – reflective practice – and I think my caring has improved since journaling.

This comment also lends support to Stopka et al.'s (2004) observation that the reflective nature of keeping a research diary and associated interviews with the researcher may potentially change the participant's cognitions and behaviour.

Meth (2003) suggests that diaries can be an empowering tool because the opportunity to write down what sometimes is difficult to say aloud relieves the emotional burden for diarists. Ciara found both the diary and the subsequent interview therapeutic

look I'll tell you what though, for me it's been really great to talk about it. Cause it also, I'm feeling lighter than I did when we started the conversation. Um, and, it's lovely to be able to have that reflection time with somebody um, particularly somebody who hasn't got any vested interests in how I am, so ...this is an opportunity to be really honest about things...I realised it would be good to talk about the caring

but I hadn't realised how much freedom there would be in it, after being able to talk, so you know, I feel like "Oh great, you know, I can say what I need to say"

However, being accorded the role of confidant or therapist by the participants can be problematic for the researcher, particularly if they do not have a clinical background. In this study, although the researcher's lack of expertise as a counsellor or social worker had been outlined at the outset of the project, she felt an increasing sense of responsibility to the participants as they assumed that she had more experience and wisdom in that area than was warranted. At the beginning of the study the participants were given a list of relevant organisations to contact should they need guidance or support during the study, however to the best of the researcher's knowledge this was not required.

Maintaining the focus

Although the study design provided valuable insight into the daily minutiae of caregiving, and as events happened, as well as the different personas of each participant, the researcher struggled to keep the interviews focused on the research topic. This highlighted the tension for the researcher who aimed to adopt an inclusive and participatory approach, while at the same time needing to focus on her own research interests. A portion of each interview was taken up with pleasantries and chit chat about what had happened in the preceding week, before moving on to the questions that the researcher wanted to ask. However, these segments of the interview that resembled everyday 'conversations' between acquaintances provided the researcher with contextual detail about the multiple facets of the caregivers' lives, rather than focusing only on her research interests. This led to the insight that the small taken-for-granted things can play a major role in the caregivers' lives. For example, in Pollyanna's case the lack of a chair disrupted her week; Roger splurging his weekly allowance, every week, on chocolate that he subsequently gave away, was an ongoing

irritant for Emily; and constantly having to remind Errol to do things frustrated Ciara, intruding into her working day to the extent that she sometimes felt that her work was suffering because of it. Having access to these details heightened the researcher's understanding of the social context for caregiving and how the apparently mundane can become unexpectedly important.

Limitations and Challenges

We have already touched on the need for flexibility in terms of offering different options for keeping a diary – written, audio or visual. Flexibility was also needed with respect to data collection, with challenges around scheduling interviews stretching out the data generation period much longer than anticipated. However, this may be attributed to the busy lives that caregivers lead, and the unexpected events that they have to cope with, rather than the study methods per se. The time factor also gave the researcher the opportunity to observe changing personal circumstances, such as hospitalisations, respite and non-caregiving commitments and how that impacted caregivers' lives. In this respect, the extended timeframe could be construed as a positive outcome. Nevertheless, our experience supports Bartlett's (2012) argument that health researchers need to be flexible and their designs adaptable in order to accommodate participants' requirements and enable their participation.

Previous studies have noted that a limitation of the solicited diary method is the considerable variation in the amount of data generated by participants. This was not an issue in this study because the follow up interviews provided the opportunity for clarification and elaboration. The different forms of data collected informed and complemented each other with the resulting depth and breadth contributing to a more holistic view of the caregivers' lives, than might otherwise be accessed using one method alone.

Conclusion

The purpose of this paper was to review the solicited diary/interview as a qualitative research method, based upon the empirical data obtained from our study of the role of emotions in the everyday practice of caring informally for older people. Using this mixed method approach highlighted several factors that support the findings from previous studies. Firstly the method worked well as a participatory approach that allowed participants to choose what, how and when they recorded their experiences. Having this flexibility and control was well suited to their busy and unpredictable lifestyles. The solicited diary provided an avenue for the participants to “actively participate in both recording and reflecting upon their own behaviour” (Elliott 1997, p.4). Moreover, this self-determined approach to information gathering meant that the participants had a greater influence over the subsequent interview than if they had only participated in a one-off interview (Spowart, 2014), as well as being able to co-analyse their diary entries with the researcher in the interviews.

The study design was conducive to the participants’ self-reflection, which enhanced their own experience of caregiving by providing valuable insights into their everyday lives as caregivers. While this may have been empowering for the participants it was also beneficial for the researchers because the diary entries alerted them to what was important in the participants’ lives as well as how they felt about it. Keeping a diary facilitated the disclosure of sensitive, emotional material that participants may have less readily discussed in a face-to-face interview and this was able to be developed via telephone interviews which also accorded a sense of anonymity. Preparing for the interviews gave rise to deeper reflection by both the researcher and the participants with the resulting collaborative construction of caregiving likely providing richer insights than an interview alone, for which the participant would likely not have prepared.

In conclusion, the prospective, mixed methods approach (Meth & McClymont 2009) was appropriate for our study of informal caregiving. We gained a richer and more nuanced appreciation of the caregivers' everyday lives because of the temporal, contextual, and multi-layered nature of disclosure. Additionally, the solicited diary, self-directed photographs and in-depth interview combination proved a valuable method for identifying conflict, and deepened our understanding of the contradictions and ambivalence associated with informal caregiving. This method has much to recommend, especially for qualitative studies exploring sensitive issues, studies involving older people, and when flexibility is likely to enhance participation.

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Link between Chapter Eight and Chapter Nine

I had planned to take a phenomenological approach to the analysis for Study Two, using Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003). IPA is a qualitative approach in psychology that aims to provide insight into how an individual, in a given context, makes sense of a given phenomenon – in this instance, emotions in the caregiving context. However, after reading through the transcripts at the end of the data collection phase it occurred to me that the participants' contributions were performative; both in diary form and in the interviews, and although co-constructed with me as the interviewer and researcher, they told a story about their perceived identities as informal caregivers. It was at that point that I decided to change to a narrative analysis.

Narrative analysis

We give meaning to our experience of time and personal actions through narrative (Crossley, 2000). During the processes of talking and writing, people join everyday actions and events into episodes that provide a framework for understanding past events and planning future actions. At the same time, we interpret our actions and experience in terms of how they relate or connect to something or someone else, as well as their moral stance (Polkinghorne, 1988). This includes stories and narratives told to each other, or constructed together.

Individuals construct narratives by selecting important events, and then sequentially organising or connecting them in a meaningful way for a particular audience (Riessman, 2008). A fundamental criterion of narrative is contingency; that is, whatever the content, events or ideas must be linked consequentially. In this respect, narratives impose a meaningful pattern on what would otherwise be random and disconnected (Salmon, 2008). By selecting or attending to certain events, thereby creating a plot, the experience becomes value-laden, or has meaning

(Cronon, 1992). Narratives are best understood as being composed for particular audiences at particular moments in history, drawing on taken-for-granted discourses and values embedded in a particular culture (Riessman). Consequently, narratives do not speak for themselves or provide a transparent view into the phenomenon under study. When used for research purposes they require interpretation, which can be accomplished in a number of ways depending on the objectives of the investigation.

Narrative analysis refers to a diverse set of methods or ‘family’ of interpretive approaches (Riessman, 2004). For example, Riessman (2008) describes three different approaches: thematic, structural, and dialogic or performance analysis. In addition each of these approaches could be applied at various levels: personal, interpersonal, positional and societal (Murray, 2000). When telling their story, narrators select what they want to say and what they do not want to say. Their stories, which are recollections of past events, are not neatly stored, intact, in the filing cabinet of their minds, ready to pull out in exactly the same form every time they are told. Rather, they are a selective re-presentation of an event or activity, narrated in a particular way at a particular time, with a particular purpose. In this way, narrators position themselves in a certain way to their audience (Murray, 2000), and researchers need to ask themselves “why was the story told *that way*?” (Riessman, 1993, p.2). At the same time, depending on how the interview process is conducted and the researcher’s point of view, the researcher’s role as listener may also be considered part of the initial narration, which is then viewed as a co-construction (Riessman, 2008).

Once transcribed, the narrative is closely read, then analysed according to the method that the analyst thinks best fits the objectives of the study. In the next step, the researcher re-presents their interpretation of the original story in the form of another story to another audience. In this way, Riessman (2008) argues that the researcher has not ‘found’ a narrative

but rather, participated in its creation. Furthermore, the audience may, given enough information formulate their own interpretation of the original story. The whole exercise therefore, becomes a series of constructions or “a story about a story about a story about a story, ad infinitum” (Gelfand, Raspa, Briller & Schim, 2005, p. xxiii). In this respect, there is no single, fixed version of truth for a particular event.

Story-telling is integral to this entire research project. The participants ‘storied’ their responses in the forum in Study One, and again in Study Two. Additionally, my analysis of their stories tells an overall story about caring informally for older people. When reading the following manuscript it is important to keep in mind that story-telling is never neutral because story tellers choose to foreground some features rather than others (Nussbaum, 2011).

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Chapter Nine: Study Two - Results

Horrell, B., Stephens, C., & Breheny, M. Informal caregiving for older people: a relational narrative of acceptance. Manuscript to be submitted.

Abstract

Informal caregiving has been portrayed as stressful, burdensome and a health risk; having the potential to provide satisfaction, meaning and personal growth; and as having both positive and negative aspects. In this prospective study, we used a capability framework to investigate the role of emotions in informal caregivers' health with six New Zealand participants who were providing care for an older person. The participants chose their own method of data collection, which included keeping a solicited diary, telephone interviews and one face-to-face interview. The data were analysed using narrative analysis. Participants drew on idiosyncratic, or personal, narratives to reveal different caregiving identities. These narratives included being a competent, responsive caregiver; maintaining a positive attitude in demanding times; and being a manager and crusader on behalf of the person being cared for. Overall, the participants' personal stories combined to create a caregiving narrative of acceptance grounded in enduring personal histories and emotional attachment. These findings affirm the relational nature of informal caregiving for older people, but at the same time point to the requirement for considering individual needs, in context, when planning interventions aimed at supporting informal caregivers.

Informal caregiving for older people: a relational narrative of acceptance

Introduction

More than forty years have passed since the first studies appeared about the adverse health effects of informal caregiving; yet, reducing the ‘burden’ of care remains at the forefront of the caregiving research agenda. Purkis and Ceci (2014) argue that, despite considerable research over that time, follow-on interventions have had a low impact in terms of reducing that burden. They suggest that it is time to question the assumptions that underpin caregiver research; including the psychological concept of caregiver burden and theoretical models, such as the stress-process model (Pearlin et al., 1990), that foreground individuals as the target for intervention. This is not to deny that caregivers struggle with the demands of caregiving. A substantial literature attests to the fact that informal caregivers do experience physical, social, emotional and financial problems, and researchers have been concerned to address these issues. However, the tendency to pathologise (Twigg and Atkin, 1994) informal caregivers’ plight has failed to advance their cause.

One of the reasons for this is that informal caregiving is multidimensional. Informal caregivers provide care for family or friends who are unable to care for themselves, thus informal, as opposed to formal, caregiving evolves from a pre-existing relationship and is located within a particular social context (Payne & Ellis-Hill, 2001). Therefore, focusing on individual deficits may be taking the wrong approach. Instead, recognising caregiving as a relational activity offers a more holistic way of understanding informal caregiving. Research that considers family relationships, motivations for providing care, and the meaning that caregivers find in providing care, will be better positioned to influence social policy concerned with caregivers’ health (see Nolan et al., 1996; Philip, Rogers & Weller, 2012).

Family and friends are increasingly being expected to provide care for older people in the community in order to meet a positive ageing goal of ageing-in-place. Enabling older people to remain independently in their community as they age is an “individualized approach to population ageing driven by the economic priorities of society” (Aberdeen & Bye, 2013, p.4). Family or informal care has become the preferred solution to elder care because it is cost effective and because caring for family and friends is assumed to be a natural response. This ‘solution’ to elder care assumes that informal or family caregivers will be willing and available to provide care. Additionally, because caring within close relationships is understood as ‘natural’ it is often assumed to be unproblematic. The relational aspect of care may be used to justify the provision of informal care, yet there is little appreciation for the diverse, and often complex, shared personal histories upon which caring relationships are based, or how these relationships unfold as caring progresses. Moreover, the range of emotions associated with caring is inadequately acknowledged or supported.

Emotions

Horrell, Stephens and Breheny (2015), found that emotions are strongly implicated in the lives of people providing informal care for older people. Emotions influenced both the decision to provide care, decision-making related to the needs of the person being cared for, and decisions about self-care. Putting the needs of those they care for ahead of the caregivers needs diminished caregivers’ opportunities to participate in activities apart from caregiving. At times this compromised the caregivers’ capability to maintain their own health.

Emotions and feelings are a pervasive feature of everyday life (Scherer et al., 2004). Described as “intentional feelings of import” (Helm, 2009, p. 251) emotions have been theorised as resulting from personal appraisals (Horberg, Oveis & Keltner, 2011) and social

interaction (Boiger, 2012), and as being involved in moral reasoning (Haidt, 2003). As such, emotions function as a key component of decision making, especially in a relational context. This implies that emotions are not only shaped by shared relational contexts, but also shape the relationships in which they occur (Boiger, 2012). Moreover, Boiger describes emotions as culturally determined. The prevailing Western cultural model accentuates an independent self that is free from others, autonomous, and bent on the pursuit of self-ish goals. This is at odds with an ethic of care perspective which emphasises interdependence, and relationality and is characterised by attentiveness to another's needs (e.g. Noddings, 1984/2013; Tronto, 1993).

The Capability Approach

Nussbaum's version of the Capability Approach (Nussbaum, 2000; 2007; 2011) provides a theoretical framework for considering the work that emotions can do, both in a positive and a negative sense, in terms of ethical judgement and ethical action (Gasper, 2014). Nussbaum's thinking covers key aspects of people's lives, emphasising the emotional content of real life stories. Her writings include an exploration of empathy and how it links to compassion. She distinguishes empathy, the ability to imagine another's experience, from compassion, which relates to feeling concern for another person's "undeserved misfortune" (2001a: 301), and argues that compassion plays a central role, related to moral reasoning, in all social life (Gasper, 2014).

Nussbaum (2000; 2007) includes emotions as one of ten central human capabilities essential for living a dignified life. Emotions are also associated with the other capabilities on her list in varying ways, as has been demonstrated in the context of informal caregiving (see Horrell, Stephens & Breheny, 2015). In this paper we report the findings from a study which aimed to provide an in-depth understanding of the role that emotions play in informal caregivers' everyday lives. Having identified the important

role of emotions in informal caregiving, we build on Nussbaum's notion of emotions as "appraisals that have an evaluative content" (Nussbaum, 2013 p.6) to consider their role in influencing caregiver's health.

Method

Recruitment

Six participants were recruited for this study, which was undertaken in New Zealand in 2013. The caregivers were recruited through the dissemination of results from an earlier study about informal caregivers' health, via the media and the various organisations that had supported the first study. The summary of results included an email address and a Freephone number to invite expressions of interest in a second study. One of the participants had already taken part in the first phase of the study.

Participants and Procedure

The participants were aged between 63 and 84 years; two women and one man were caring for a spouse, and two men and one woman were caring for a parent. The ages of the cared for ranged from 64 to 92, with illnesses including heart disease, stroke, morbid obesity, Alzheimer's disease and a rare terminal illness. The method of data collection for four of the participants was the diary/interview. This involved the participants documenting their daily activities and feelings for varying lengths of time. They chose their own method of documentation, which included keeping a hand written journal, sending regular emails, word documents and photographs. This information provided a resource upon which to focus subsequent, multiple open-ended interviews between the first author (BH) and each participant. Once she received each update, BH contacted the participant and organised a

telephone interview, which was recorded and transcribed prior to analysis. Two of the participants chose not to complete a diary. One completed a single face-to-face interview; the other took part in four telephone interviews at periodic intervals over four months. In total 27 interviews were completed, with times ranging from 28 minutes to 1 hour 20 minutes. Interviews were scheduled around the participant's caregiving commitments. Originally an interview each week for six weeks was planned, however, caregiving commitments meant rescheduling for some participants, so involvement with the study varied from 7 weeks up to several months. These procedures were approved by the University Human Ethics Committee.

Analysis

Narrative methodologies have been increasingly used as a means of understanding real life experience (Mishler, 1986) within a meaningful context (McCance et al., 2001). Narratives are most likely to result from unstructured interviews utilising open questions which encourage participants to respond more freely (Mishler, 1986). In this study where participants had kept a diary, the diary excerpts were used to focus open questions, for example by asking the participants to "tell me more about..." While a narrative may be "any spoken or written presentation" (Polkinghorne, 1988, p. 13), the narratives presented here tell a story about events that the narrator considers are significant (Denzin, 1989), contextualising everyday experience and conveying core values (Gasper, 2014) of caregiving. The narratives reflect Benner et al.'s (2009, p.284) definition of 'constitutive narratives' found in nursing which "are usually linked to larger cultural stories and notions of good embedded in the larger culture". It should be noted that these narratives were co-constructed in an interactive process with the interviewer, and therefore should not be viewed as the only personal narrative available to each participant (Riessman, 2002). Additionally, "storytelling is never

neutral” (Nussbaum, 2011, p. 15) as the narrator inevitably has a ‘particular’ story that they want to tell. In this sense, narratives take on a performative aspect (Langellier & Peterson, 2004).

Following transcription, the interviews were closely read several times by BH. At this stage, it became apparent that the participants each had a particular way of telling their story about caregiving. This was reinforced by the temporal methodology used for the study, in that it was possible to check for consistency not only across one interview, but over the course of sequential interviews conducted over an extended timeframe. Additionally, where participants had sent in diary excerpts analysis also involved moving back and forth between the excerpts and the transcripts to compare and clarify data, which assisted with interpretation. Narratives were considered to be sections of talk that described a particular event or experience, and had a beginning, middle and ending, or resolution.

The analytic process involved identifying key narratives within each of the participant’s interviews. Key narratives develop from important events or processes in people’s lives (Boenisch-Brednich, 2002) and are easily identified as themes that repeatedly surface in an individual’s stories (Phoenix, 2008). In this sense, these themes represented the social identities (Somers, 1994) that the participants chose to disclose in this study. In this way the participants revealed their preferred identities (Riessman, 2002), in the context of a study about caregivers’ emotions. This does not mean that these were the only identities taken up by the participants. When the narratives were checked for consistency contradictions were noted, which suggested that the participants struggled at times to maintain a cohesive sense of a caregiving self. Although the interviews focused on the role of emotions in the everyday lives of the participants, the key narratives did not always explicitly address

feelings. For example, stories related to the participants' decision-making may not have mentioned specific emotions, but for analytical purposes were assumed to be underpinned by bonds of affection. Once the participants' key narratives had been identified, the data was compared across participants' to develop a common narrative of caregiving.

Results and Discussion

Narratives of caregiving

The overarching story told by all six participants was that they valued being able to provide care for someone with whom they shared a pre-existing, affectionate relationship. While each participant told their own personal stories (Murray, 2000) about their particular experience of caregiving, we identified a prevailing narrative of acceptance that was common to all of the participants. Although the participants' lives were not free from stress, this central story offers an alternative conceptualisation of caregiving, which 'troubles' a dominant cultural narrative that valorises autonomy and the successful accomplishment of individual projects, particularly in regard to health. Below, we present each participant's personal story followed by a discussion of a shared key narrative of caregiving that has implications for the way we understand informal care for older people. All of the names used are pseudonyms.

Pollyanna's story

Pollyanna was a 66 year old caregiver for her spouse Bob. The complications associated with Bob's multiple co-morbidities meant that Pollyanna was faced with ongoing caregiving duties. Although Pollyanna was the primary caregiver, she also had her own serious health issues that saw her hospitalised during the course of her participation. Pollyanna had also participated in the first phase of the research. She was the only participant

to choose self-directed photography, accompanied by explanatory text and emails, as a method for documenting her caregiving activities. Pollyanna completed six interviews over an eight week period.

The glad game: “my brave face and false smile”

Pollyanna’s choice of pseudonym reflected her approach to caregiving. In one of her first emails she said *“I am here and doing just fine...about to put my smiley face on and get on with what must be done. I wish it was as easy as clicking on a key”*, and inserted the smiley face emoticon. This theme recurred throughout her participation in the research. Reflecting on this in her interviews, she acknowledged that *“holding myself together for everyone else”* had become second nature. In this sense, Pollyanna had an underlying belief that you should *“Set your mind that no matter what is going on in your life, you’ll have a good attitude”*. This attitude to life was the coping strategy that she used when caregiving demands got tough, and was evident in what appeared to be a well-rehearsed repertoire of responses to questions about being Bob’s primary caregiver. When asked why she continued to care for Bob when she clearly had her own health problems she said replied *“Well, we got married; we made vows that we will be together through thick and thin, sick and sin. And we’ve been through all those, you know”*. She had made an almost identical comment in the first phase of the study. Noting this ongoing consistency in her story suggested that Pollyanna’s commitment to her relationship with Bob was a default position that she used to explain her role as Bob’s caregiver.

One of the reasons that caregivers find it difficult to ask for help is because they are invested in maintaining an identity as capable and coping. When asked if she found it difficult to ask for help Pollyanna replied *“I think I do, yes I do find it quite hard. The only people I usually tell [when I am unwell] are the people that are not well themselves, so they*

can't help". In another interview she said, *"I've always been an 'I can do' person, 'um, I don't want to be seen as a needy person, or a 'not able to cope', yeah"*. She related this back to an incident that occurred when her children were little

I once went to my doctor and I said "I think I'm going to have a complete breakdown." This was years ago... I go off to my doctor I sit in his office and I couldn't even cry and I said, "I think I'm having a breakdown." And he says "You won't, you're not the type." Yeah, and I thought "Geez! I can't even have a breakdown!" And I think he was right...

These comments suggest that Pollyanna's resistance to receiving help is most likely related to her self-perception as a competent caring person, rather than feeling obliged to care for Bob or guilty for putting her needs before his.

"I think it's a need to help"

Pollyanna described herself as *"a helpful kind of person, reasonably sensible"*. And for this reason she not only cares for her husband but is also heavily involved in community groups, charity work and an online support group. She described her husband's concern that even when she was unwell she was unable to say no to requests for help. Her family remonstrate with her for feeling so dutiful, both to their father and in the community, saying *"don't 'should' on yourself, Mum"*. Pollyanna explains her involvement as a *"need to help"*. Although she believed *"you can feel sorry for someone or empathise with them but not feel you're obligated to fix it"* she described herself as a *'fixer'*. Having co-founded an online support group in recognition of others' needs, she related a recent occasion when she private messaged someone saying, *"How best can we help you get through this? You know, can we as a group help you to get through this. And I was the first one to respond to her that way..."*

yeah”. Pollyanna acknowledged that belonging to the group is a kind of support for her too. It would seem that the support group provides social interaction and intellectually fulfils her ‘need to care’ without having to leave the house.

Ciara’s story

Ciara was 63, single and living in her father’s home as his primary caregiver. She kept a hand written journal, scanning or posting the pages weekly to BH who used the information to focus their six interviews. Ciara chose an Irish name as her pseudonym because it sounds like ‘carer’, which like Pollyanna, provides insight into how she perceives her caregiving role.

“An over-developed sense of empathy”

Ciara acknowledged that being a carer is “*part of the way I define myself*” and although she has other roles such as mother, grandmother and self-employed business woman, she admitted that she worried about how she will cope when her father dies, leaving her “*not being able to be a carer*”. Being a carer meant many things to Ciara. For example, she repeatedly spoke about how she is constantly “*tuned in*” to her father’s needs. She told the story of suddenly waking up in the middle of the night and thinking about Errol’s alarm. Her grandchildren had been visiting and she thought they may have turned it off

And it was off. And I thought “Oh my goodness” you know, there I was fast asleep but somehow, something in my brain went: grandchildren here today, has the alarm system you know, been turned off and will you hear Errol? And I thought isn’t that totally amazing that that can happen. Um, your brain is just working away while you’re asleep and then it drags you out of sleep and you go and check and you think

“Crikey! That was good.” Um, I was sort of really um, yeah on guard sort of vigilant, looking out, helping...

Another reason for Ciara telling this story was because it provided evidence of her competence as a carer (Tronto, 1993). Providing basic care for Errol was not sufficient for Ciara. She wanted to be *“a carer in the way that means that the person that you’re caring for really gets looked after well”*. For Ciara this not only meant ensuring that Errol eats well and is warm in the winter, but also meant being attentive and responsive to Errol’s changing needs, providing stimulation, getting him out of the house, and ensuring that he does what he can for himself and for Ciara.

Ciara often spoke about constantly trying to put herself in Errol’s shoes and anticipate what he might need next or what she needed to do next. She wondered if it was possible to demonstrate too much empathy and illustrated this thought with the following story

So for instance, this morning, sometimes my dad has flatulence and I can go into his bedroom in the morning and it’s smelly and I think “Right, need to open the windows cause I don’t want that like that when the nurse comes”. So, sometimes I think I’ve got overdeveloped empathy cause you know, you know I don’t just go “Oh well, she can deal with it”. You know, but no, I need to fix that up.

This excerpt highlights that Ciara’s ability to anticipate the situation of another is not only directed at Errol. Ciara sees herself as an empathic person, which helps to explain why she so readily adopted the role of caregiver and has continued in this role, putting Errol’s needs ahead of her own.

The “completer finisher”

Although she went to great lengths to deny that she is a perfectionist, Ciara admitted that she is driven to “*make sure everything can be as good as it can be*”. She said “*I’ve got quite the strong sort of completer/finisher type approach to things, like if I start something I need to finish it off so it’s completed. Cross the t’s and dot the i’s etc*” which carries over into the way she cares for Errol. She realises that she has high expectations for herself and how she cares for Errol, but she is driven by the thought that when he is gone she needs to feel that she has done the best possible job of caring for him. She believes that

this person that you’re caring for is much more vulnerable usually than the carer physically um, and so you want to do everything you can to make that easier for them. And that whole thing I know for me, this person’s nearly at the end of their life I want to make it as good as possible...

However, as time has gone by Ciara has become less vigilant and more relaxed about how she cares for Errol. Realising that she cannot prevent her father’s death, but she can manage his care in a way that is respectful and loving leaves her feeling satisfied that she has completed a job well done. Allan’s and Emily’s stories were similar to Ciara’s in that being able to provide good care was important to them. However, their personal narratives were more ambiguous than the other four participants.

Allan’s story

Allan was a 63 year old caregiver for his wife of 38 years who has a rare terminal illness. He had given up work to care for Anne; although he was assisted by formal caregivers who helped with Anne’s personal care and sat with her so Allan could take time off and get out of the house. He had “*gone through*” about forty caregivers before settling on

a team whom he felt could provide the right kind of care for Anne. Allan prepares special meals for Anne (she can only eat soft pureed food) which he feeds to her himself. He often feels too tired or can't be bothered to cook for himself, so he orders takeaways. We interpret Allan's story about caring for Anne as a story of devotion.

When asked about why he gave up work to care fulltime for Anne, Allan said, "*I wouldn't dream it of any other way. No, we had a bit of, a pretty bad experience and um, when I had to take Anne to hospital, and I thought "Wow, god, I can't handle this". No, no I'm the best one to do the job"*. He says that he finds it very hard to switch off from his caregiving role

I mean yeah, I've got all the support um, I can have, but, it's really weird. Ok, you get two hours in the afternoon and you go out and you do whatever you're gonna do and you come back and you don't feel as if you've really had a break. You just come back and you get on with what you've got to do again. And it's even the same when my daughter comes over and I go away for a few days. Um, it doesn't leave your head, you're constantly thinking "Is she alright?" you know, and this, that and the other. It's just there continually. And you can't get, you just can't get away from it.

Allan said that he had no choice regarding taking on the caregiving role, but at the same time he didn't want a choice and would never consider residential care for Anne

I mean I'm quite happy doing it um, she deserves it and you know, if that's what she wants then that's what it will be... if her brain had gone then it'd be a different story, but all the time she knows where she is and what's going on, I don't want to do it.... I'd feel very sad about it, I wouldn't feel guilty I'd just feel... I'd feel very

uncomfortable about it. Yeah, I'd just be constantly thinking "Is she alright?" and I know she wouldn't be very happy".

Allan and Anne have developed their own means of communicating which tells Allan that Anne is aware of her surroundings. Due to her limited functioning, Allan has adopted the role of thinking and acting on Anne's behalf and because of their deep and long-lasting attachment he cannot make a choice for Anne that he knows she would not make for herself. In telling this story, Allan emphasises that his sense of wellbeing is strongly connected to Anne's wellbeing and needing to feel that he has done what is best and right for her.

Emily's story

Emily's situation was different from the other participants in that she had cared for Roger for more than twenty years, but when she had a stroke (a few months before the study commenced) Roger went into residential care while she recuperated. At the time of the study he was refusing to come home, but Emily said she will have to bring him home as she can no longer afford the money for his care. Emily was adamant that if she had not had the stroke he would not have required formal care. She rings Roger every day, attends community activities with him and has him at home, often overnight, at least once a week.

Emily, aged 84, was determined to tell an alternative story of caregiving. She described her relationship with Roger as "*atypical*", although she said "*we get along quite happily after 60 years*". She said she initially felt "*peculiar*" about Roger going into care and living alone for the first time in her life but now she finds that it is "*liberating, it's marvellous! Isn't that awful?*" Like Pollyanna, Emily tended always to adopt a positive attitude. In her last communication she said "*I'm glad this week is over. [But] despite*

everything going wrong I'll wake up tomorrow and feel as cheerful as usual to enjoy another day – even if it's raining as predicted”.

Emily portrayed herself as an independent, pragmatic person who worked and pursued her own community interests while caring for Roger

I used to say that he [Roger] suffered from um, oh I had a phrase for it um... benign neglect. Which um, because... but then when I see other people being treated at Stroke, women you know, might as well have martyr written on their forehead... I was never going to be like that.

However, at the same time the following conversation suggests that Emily cannot stop feeling responsible for Roger

Because when he's here, I find I'm so much more alert to him, the whole time I'm thinking, it's like the mother with the baby, you know, you're never ever free when they're little, uh, responding to them. I mean you're just somehow linked.....

This theme of being mentally attuned surfaces repeatedly in the interviews as Emily describes not being able to switch off mentally. Given Roger's impulsivity she has spent the last few years “*anticipating trouble, or trying to avoid problems*”. She said she finds this mental activity more tiring than physical exertion and frustrating, but it is not easily remedied because of their emotional connection.

Additionally, despite her protestations that she is not going to be a martyr to caregiving, Emily made the following observations when queried about her decision to change her arrangements to accommodate others' plans:

P. Well she'd already done it, she'd already got her arrangements made and I didn't like to disappoint her. And it was only me going to be going to the concert, another niece was going to take me.

R. You just said "only me". Aren't you important too?

P. I know, I am, but then... I thought of all the other... I spend all my life it seems, making arrangements. You know, for him to come over it's so complicated... Yes, I feel lately, I've felt that my life has been run along the lines of making his more comfortable.

In this sense, Emily's role as caregiver resembles that of a manager, which is echoed in Doug's story below.

Doug's story

Doug was 66 and caring for his elderly mother from a distance. Because he was not living in the same city as his mother and was not responsible for her day-to-day care, Doug felt that he would struggle to write a useful weekly journal and therefore negotiated to contribute to the study with regular telephone interviews. Doug's main role was to manage his mother's finances, while his brother who lived in the same city as their mother was responsible for her day-to-day needs. Together, they managed a preventive health regime for their mother. In this sense, Doug's personal story initially appeared to be about management. However, in every interview Doug told the same story about changing his lifestyle more than forty years ago when his former wife became sick and became a complementary health practitioner. After attending overseas courses related to healthy living, he began running marathons, started eating healthy foods and taking supplements.

The Crusader

Doug's past experience, beliefs and lifestyle influenced his crusade, on his mother's behalf, against the medical profession. His series of interviews turned into an ongoing account of how the new supplements and dietary changes were working and how his mother's health was improving by "*getting her onto supplements, getting her off drugs and then sort of um, tidying up the process so that it uh worked as best as possible*".

Doug was careful to position himself as responsible, describing extensively researching his mother's drug regime and his concern about the interactions between many different drugs. He told a long story about challenging the doctor's decision to give his mother certain drugs based on the results of research carried out on middle aged men, concluding

I mean, after I had that session with her doctor and saw the focus there I thought supplements have got to be a better choice if it uh, uh, improves her life. And I mean, we weren't saying "There's no way we're gonna stop her drugs." We're saying let's increase her supplements, decrease the drugs and if everything looks better we'll go down that path.

Doug positioned his approach as encouraging his mother to try complementary therapies but always remaining cognisant of his mother's wishes. He described having a more considered and responsive approach to his mother's care than his brother's uncritical enthusiasm for trying something new, suggesting they should "*back off*" when a particular therapy appeared to overwhelm her. Doug and his brother had both approached his mother's care from a preventive point of view. Doug anticipated more intensive, hands on care as his mother (who is already 91) ages, but he believed that, "*if we can improve her health a bit perhaps we*

won't be faced with that question or that responsibility". In the end, Doug's motivation was to improve her quality of life.

Ian's story

Ian's approach to his mother's care was very similar to Doug's strategy; in this sense his story also relates to being a crusader. Ian and his wife were caring for Ian's mother who had been diagnosed with Alzheimer's disease. Ian was not interested in completing a diary, or a series of ongoing interviews. He had a particular point to make, which became immediately evident in his one face-to-face interview. He said, *"I don't belong to that category of people who will accept what doctors say"* and continued to describe the regime that he and his wife have implemented to improve his mother's health. Like Doug, Ian was not trying to find a cure for Alzheimer's disease, however he was very concerned to improve and maintain his mother's quality of life. He described the very careful research that he had done and daily documentation of her progress, noting that his mother no longer acted like a *"zombie"* and was no longer confined to a wheel chair. She was able to walk to the park, dance and sing and was generally much more interactive and happy. He was so eager to share his experience that he said *"If you come across people who will be interested, I have a request, just give them our telephone to call us directly. Don't, you don't need permission to do that, just give them the phone [number]"*.

When asked why he chose to bring his mother to live in New Zealand rather than organising residential care for her in her own country he replied:

...it will be very difficult for us, the family, to deal with the idea that we aren't, let's say, able to take care. In a way, when such situations... we come across such situations, a member of the family needs our help, if you don't give it then, when

then? When can you say that “Oh, I helped a member of the family” if not when that person needs your help.

Ian was quite clear that there was nothing special or heroic about this decision, saying

We live in a world where unfortunately the majority of people need a hero, and if they don't have it they'll make it [whereas] It's just probably a matter of luck, you have only one mum, she needs your help, that's it.

Ian clearly had a strong bond with his mother and wanted her to have the best quality of life possible, yet his attitude towards his responsibility for her care appeared understated and matter of fact. One way of interpreting this was that he had a quiet acceptance of his role as caregiver. This is highlighted in the exchange below.

“That’s the way it is”

When asked how caring for his mother had affected his life, Ian responded

*P. Oh, god, in many ways. One of the things that comes with it, it's lack of freedom, freedom, as much as we can be free in this world really. Uh, *pause* Yeah, that's probably the most obvious in changes, yeah, change.*

R. And in what ways, with your freedom?

*P. We can't for instance, go out much, not out what I mean by this, not a restaurant, because we don't go at all, for walks, or to visit other friends. We're, we were *laughs* quite social orientated with people.*

R. So, how does that make you feel not being able to maintain those friendships?

P. It's mostly all the time, it has to be acceptance, we chose for it. So that's the way it is, that's the way it is, you can't have them all.

R. Mmm, so it's more important for you to be doing what you're doing for your mother than it is to be doing anything else?

P. I don't know if it's a matter of importance, as more as it's one of these things, look, that's the way it is. I don't see it as it's more important than that, but that's the way it is.

Although Ian completed only one interview his comments reflected the personal narratives of the other five participants. Because of Ian's ongoing reflexivity in his daily life, he was able to articulate very clearly what the other participants revealed during co-analysis with the researcher in the interviews based on their diary entries. In this way, Ian's narrative of acceptance resonates with the experience of all of the study participants, although others may have been less explicit in naming it.

Ambivalence

Overall, the personal narratives of all six caregivers exemplified attentiveness, responsiveness and competence which are three of the ethical principles of Joan Tronto's (1993) ethics of care. Although they spoke about the practicalities of giving care, their self-identification as caregivers exemplified the 'caring about' aspect of care. However, examples of love and care do not tell the complete story about informal caregiving. All of the participants expressed negative emotions about their caregiving role, and especially tension around decision making. Having to accommodate caregiving into their everyday lives meant that the participants often chose not to do things for themselves in preference to providing care for a loved one. For example, Ciara was regularly too tired to exercise or go to dance

classes which she enjoyed. She rarely found time to run anymore, yet she had been a runner for 30 years. Allan had sold his hospitality business to become a fulltime caregiver and now had a very limited social life. Ian's social life had also diminished since he started caring for his mother. Pollyanna was the only participant to explicitly state that caregiving did not stop her from doing what she wanted to do.

However, coping with Bob's personal care needs was a source of tension for Pollyanna. Conceding that she is "*not always nice*" she explained by saying

Oh, I grumble, you know, cause he'll tap on the wall when I'm still watching T.V. He's tapping on the wall because he can't get in bed by himself. He's got to a certain point where he taps on the wall and I grumble all the way from the lounge to the bedroom saying stupid fat bastard

At the same time, Pollyanna feels guilty about his weight because throughout their long marriage she has been responsible for his meals.

Both Pollyanna and Allan have had to cope with their spouses' bowel troubles. Pollyanna explained that Bob has a problem with bleeding and it is up to her to insert his suppositories. She says

it's not much fun having to put a suppository up someone's bum. That's where I get cranky... And he finds that humiliating too. [But] I just do it, although, you know, as this week he's noticed I'm a bit cranky about it and yeah, um, and he says he's too scared to remind me so he goes off and sits on the edge of the bed until I get there. And I'm thinking "Oh he's gone to bed tonight, I don't have to do it tonight." You know, and then I get there and he's just sitting on the bed looking a bit woeful. But I said, "Do you want a bullet put up your bum or, you know...?" And he goes, "Yeah,

I'm sorry but I think you'll have to." So then there goes the running report you know, the next morning on how well it's worked and yeah.

Although Pollyanna said she always wanted to be a nurse, being a wife changes the dynamics of what is an essentially nursing procedure. She said that she would find it easier to do that kind of thing for a stranger. Allan was resigned to doing the same for Anne but said it makes him feel

*... like shit *laughs*. I don't want to do it but I can't leave her lying there with all that. I don't, I just think "Oh, god" and then I just get on with it. Um, I don't have a choice really.*

R. *Would you rather not do it?*

P. *If there was another choice, yeah, you know, it's a horrible job.*

These are the types of things that cause strain for the caregivers, but compassion and commitment, embedded within an extended personal history with the person being cared for, helps them to accept it, deal with it and move on. This then is the central story of these caregivers' care for loved ones.

Acceptance

A narrative of acceptance provided an overarching account of care provision by the study participants, and relates to the attachment felt by the caregivers to the person being cared for. The participants were engaged in a continual process of adapting throughout the caregiving process, highlighting that they had accepted their caregiving role because they cared about the cared for person and would therefore do what it takes to see that through. The study methodology was instrumental in generating this insight. The temporal design enabled

a comparison between the two different, but complementary, methods of data collection. Keeping a diary provided a snapshot of the minutiae and travails of everyday caregiving, while the follow up interviews, which facilitated in depth discussion about the events and experiences that were recorded in the diaries, provided a broader account of caregiving. Via this process the participants were able to articulate a caregiving narrative that highlighted the emotional and relational nature of caregiving. This narrative provides insight into caregivers' choices, particularly with regard to continuing to provide care when they were clearly suffering from stress or in poor health themselves; choosing not to accept outside support; and sacrificing their own needs and activities in order to provide care for a loved one. As Ian commented

my well-being, is dependent on her well-being. If she's alright, I will be alright. I would not be a carer anymore. It's simple like that. So in this situation because you can't... if she's not right I'm also not right. So to say that ok, the best way will be to whatever, to go on holiday, it doesn't make any, to me, any sense...

This comment offers an alternative, relational definition of wellbeing and echoes Nussbaum's (2007, p. 158) observation that "the good of others is not just a constraint on this person's pursuit of her own good; it is a part of her good". In this respect, interventions that focus on the day-to-day problems faced by caregivers and their overall wellbeing in terms of individual restrictions or accomplishments neglect the relational context for caregiving.

These findings suggest that interventions intended to support informal caregivers might benefit from a different approach to planning that acknowledges the relational aspect of caregiving. That said however, it is important not to subsume the caregiver within the

caregiving relationship. The CA reminds us that consideration of an individual's circumstances is paramount, but this cannot be achieved without taking the social context for those circumstances into consideration.

Conclusion

Philip, Rogers and Weller (2012, p.2) argue that the provision of care should be of public concern as caregivers are “often are poorly paid, marginalised and socially restricted”. Moreover, in accord with Nussbaum's (2000) view of individuals as ends not means, concern for caregivers' wellbeing should be based on concern for them as individuals, not as resources in a caregiving industry. Yet, somewhat paradoxically, attending to individual caregivers' needs necessitates viewing their 'plight' as embedded within complex webs of interdependent relationships. This is at odds with a dominant narrative in today's society that foregrounds autonomy and independence. The findings from this study support MacDonald's (2002) argument that a concept of autonomy based on individualism and independence is untenable in the context of health care for older people. The participants' narratives demonstrate that individual choice and independence is irrelevant, because caregivers' decisions and actions occur within a relational context. Therefore autonomy is better understood as 'relational autonomy' (see Donchin, 1995; Sherwin, 1998).

The term relational autonomy may appear, at first glance, to be an oxymoron, however as Nedelsky (1989, p.12) argues, “Relatedness is not, as our tradition teaches, the antithesis of autonomy, but a literal precondition of autonomy, and interdependence a constant component of autonomy”. Recognising that humans are deeply interconnected and interdependent, autonomy is thus reconceptualised. This resonates with Barnes, Taylor and Ward's (2013) argument that wellbeing should be understood as the product

of relationships and interactions, rather than an individual state of being. Moreover, they argue that this finding has important implications for wellbeing research and social policy. If we understand individual autonomy as socially structured, (MacDonald, 2002), this points the way to social change by advocating a re-construction of autonomy as relational. Such an approach would not only help to reconfigure support for informal caregivers, but bringing into focus the value of “love and care as moral abilities” (Nussbaum, 2000, p.249) would generate ethical policy and practice.

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Chapter Ten: Capability to care and work - when dual roles intersect

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Chapter Ten is the final manuscript. It combines the data from both studies in an exploration of the intersecting roles of unpaid care and paid employment. This article discusses the issues facing caregivers when faced with reconciling work and eldercare and demonstrates the complexities around caregivers' options and the choices they make. In particular, it highlights the relational aspects of decision-making, which Gilligan identified more than thirty years ago, and has informed feminist writings about caregiving ever since.

Abstract

Ageing in place is a cost-effective policy solution to eldercare that reflects a dominant positive ageing discourse of choice and independence. It satisfies older people's preference to remain at home and be involved in their community, but depends upon the provision of care and support for frail elders, particularly the oldest-old, who require assistance to achieve these goals. The traditional provision of unpaid eldercare by female relatives is changing as women are increasingly working outside the home, and they have to choose between, or manage, dual roles of caregiving and paid work. Negative effects on health, paid employment, and finances are associated with the intersection of eldercare and employment. Solutions involve reducing or relinquishing paid employment, which would have financial, social, physical, and emotional ramifications in the future. However, being able to

successfully accommodate both roles provides a sense of satisfaction and fulfilment. To understand the complexity of managing the tension between work and eldercare requires a detailed analysis of unpaid caregivers' daily lives. This paper presents findings about eldercare provision and paid work, derived from two qualitative studies that used a participatory methodology for an in-depth exploration of caregivers' health. The participants' stories demonstrate that rather than reflecting on access to a range of options, caregivers' choices are constrained, and involve trading work and other capabilities for the capability to care. Providing care for a loved elder was the first priority, followed by paid work. Having the capability to maintain a healthy and balanced life was the caregivers' lowest priority. Unpaid informal care has benefits for elders, and it is a valued emotional relationship for caregivers; however, future social policy should address the difficulties that caregiving creates in people's lives along with focusing on the benefits that such care offers in terms of positive population ageing.

Introduction

Ageing in place is a preferred response to eldercare (Rolls, Seymour, Froggatt, & Hanratty, 2011). It provides a cost-effective policy solution to housing an ageing population (Sixsmith & Sixsmith, 2008) and reflects a dominant positive ageing discourse of choice and independence (Bebbington, Darton, & Netten, 2001) by satisfying older people's wishes to remain at home and be involved in their community. Ageing in place depends upon the provision of care and support for frail elders, particularly the oldest-old, who need assistance to live at home and remain socially engaged (Barrett, Hale, & Butler, 2014). In the United Kingdom, more than 60 percent of elders are cared for by unpaid family, friends, and neighbours (Pickard, Wittenberg, Comas-Herrera, King, & Malley, 2012). In previous generations, elders often lived in multi-generational households, and

care was provided by female relatives, for example, by stay-at-home wives, daughters, and daughters-in-law (Gross, 2011). However, this traditional solution to eldercare is changing because of shifting social and economic forces. Changing family structures, employment trends, and retirement policies are altering the availability of informal caregivers to provide care (Haber Kern, Schmid, Neuberger, & Grignon, 2011).

Current policy objectives simultaneously promote women's workforce participation and the privatisation of care (Bittman, Hill, & Thomson, 2007), therefore many women, who were traditionally available to provide family care, are now working outside the home. Consequently, a growing number of working caregivers have to choose between informal caregiving and paid work, or manage dual roles (Hammer & Neal, 2008). In addition, caregiving responsibilities are often divided between concurrent care for children and elders (Kossek, Lewis, & Hammer, 2010). Previous research has identified difficulties associated with combining eldercare and employment (e.g. Calvano, 2013; Eldh & Carlsson, 2011), especially when the need to provide care first arises or increases (Spiess & Schneider, 2003). Caregivers at greatest risk for care-related employment consequences are women, men caring for a spouse, those approaching retirement age, those in poorer health, and people spending more time performing care tasks (Fast, Dosman, Lero, & Lucas, 2013). Previous studies of the tension between combining work and family responsibilities have focused more on childcare and caring for adults and children with a disability and less on providing eldercare (Bittman et al., 2007). Consequently, there are fewer workplace initiatives to support care provision for frail elders, despite the demands of eldercare provision, which can be fraught with crises and is potentially more stressful than child care (Koerin, Harrigan, & Secret, 2008).

Three main areas of concern regarding working caregivers have been identified,

namely the negative effects on health, paid employment, and finances. Managing multiple responsibilities has physiological and psychological costs, such as depression, anxiety, or burnout (Gordon, Pruchno, Wilson-Genderson, Murphy, & Rose, 2012). Informal caregivers juggling the dual roles of caregiving and paid employment report lethargy, fatigue, lack of concentration, and worry about caring responsibilities while at work (Arksey, 2002), which includes feeling guilty for providing insufficient support to the care recipient (Eldh & Carlsson, 2011). Maintaining these roles is associated with risky health behaviours, such as increased alcohol or drug use, sleep deprivation, inadequate nutrition (Shoptaugh, Visio, & Phelps, 2012), and poorer emotional health (Bookwala & Schulz, 2000). Juggling caregiving with work may cause caregivers to delay their own medical treatment (Conway- Giustra, Crowley, & Gorin, 2002). These factors have long-term implications for caregivers' health, increasing their susceptibility to physical illness, including hypertension, pulmonary disease, cancer, and cardiovascular disease (Shoptaugh et al., 2012).

The more intense the caregiving demands, the longer the duration, and the fewer the resources at the caregivers' disposal, the harder it is to combine full time employment and caregiving responsibilities (Kim, Ingersoll-Dayton, & Kwak, 2013). In order to cope with their dual responsibilities, working caregivers rearrange their work hours, take unpaid leave of absence, or use their annual leave (Barrett et al., 2014). They may choose lower paying or part-time jobs, which reduces their career prospects (Arnsberger & Lum, 2008), leading to difficulty in returning to the workforce (Bourke, 2009). Many older women involved in caring for a spouse or parent are often reluctant to disclose the extent of their care work for fear of discrimination in the workplace (Barrett et al., 2014).

Unpaid caregivers are more likely than the rest of the population to reduce their hours of paid work or withdraw from the labour force altogether (OECD, 2011), and women are

more likely than men to give up work in order to care (Ben-Galim & Silim, 2013). The resulting loss of income is significant, having a detrimental effect on earnings that may accumulate over a caregivers' lifetime, and extend beyond the caregiving period (Bittman et al., 2007). Spouses or partners, who are generally the first to be involved with care provision, may take early retirement, especially if they begin caregiving close to retirement age (Fast et al., 2013), which reduces their financial provision for retirement (Evandrou & Glaser, 2003, 2004). Alternatively, they may have to work beyond retirement age to support a dependent spouse.

While combining caregiving and work may be a struggle, positive effects have been documented when caregivers are able to successfully manage the two roles. Employment provides an income and contributions for future retirement (Evandrou & Glaser, 2003) enabling greater financial security. Employment helps to maintain social networks, which benefits emotional wellbeing (Arksey & Glendinning, 2008) and provides respite from the caring role. Being able to engage in paid work enhances self-esteem and provides opportunity for interaction with workmates, which helps to ease the burden of caregiving (Arksey, 2002). Combining work with caregiving also offers opportunities for personal growth (Saunders, 2010). In this way, paid work can have beneficial effects on caregivers' physical and emotional health (Pickard, 2004).

Understanding the complexity of managing the tension between work and eldercare requires detailed analysis of the daily lives of informal caregivers for older people. The studies described here aimed to provide an in-depth exploration of how informal caregivers manage the dual roles of paid work and eldercare.

Method

Methodology

Understanding what people value and how well they are doing requires rich, contextual information, which involves giving people an opportunity to discuss what they value (Sen, 1985). Therefore, both studies presented here use a participatory methodology to develop knowledge in the context of eldercare. Participatory research facilitates knowledge production with participants that is grounded in their first-hand knowledge of the research topic (Heron & Reason, 1997). The current studies aimed to engage with the participants in “democratic dialogue as co-researchers and as co-subjects” (Heron & Reason, 1997, p. 8). A key characteristic of participatory research is emergent design (Herr & Anderson, 2005), which accords with the hybrid approach (van Ootegem & Spillemaeckers, 2010) used in this study. The first study used an online forum, which was created specifically for the study. Via the forum, caregivers were invited to contribute their thoughts and feelings concerning what they considered important for maintaining their own health while providing eldercare. Results from the first study informed a second study, which focused on the daily lives of informal caregivers for older people. This paper presents findings from both studies regarding the intersection of dual roles: the capability to provide care and the capability to engage in paid employment.

The Capability Approach (CA; Nussbaum, 2007; Sen, 1980) provided the theoretical framework for both studies. The CA is concerned with the freedom people have to lead the type of life they have reason to value (Sen, 1980), and it provides a useful basis for examining health (Venkatapuram, 2011) in terms of how well people can achieve valued activities. Within the CA, capability refers to the freedom people have to achieve outcomes that they value (Alkire, 2005). Consequently, the capability to care describes the ability to engage in caregiving as a valued life path, and the capability to engage in paid

employment is the freedom to pursue employment. Nussbaum (2000, p. 244) argues that the CA “provides the best framework within which both to value care and give it its necessary critical scrutiny.” The CA considers people’s ability to live well across all spheres of life, scrutinising not only personal characteristics but also the political, social, and economic environment.

STUDY ONE: CARERSVOICESNZ

Participants and procedure

Participants were recruited via the various websites and networks of New Zealand caregiver organisations, caregiver support groups, and organisations associated with the chronic illnesses of old age. To be eligible for the study, they needed to be caring for an older person in the community. Over 4 months, 60 caregivers took part in the forum. To protect their anonymity, the participants were asked not to provide demographic details and to use pseudonyms. However, contextual background details from the participants’ postings revealed ages ranging from late teens through to mid-60s, with only two participants identifying as male. The participants included spouses, daughters, a son, a granddaughter, and non-kin caregivers, and were caring for people with various illnesses associated with ageing, including Alzheimer’s disease, Parkinson’s disease, heart disease, and cancer. Some of the care recipients had co-morbidities, and several of the caregivers were caring for more than one person.

An online forum, *carersvoicesnz*, was created specifically for the study, and it provided an opportunity for caregivers, who are often socially isolated, to meet as an online community to facilitate the collective sharing of experiences via a set of discussion boards. The evolving, anonymous discussions aimed to meet Sen’s (2004) requirement for democratic process specific to the context of informal eldercare, as well as to ensure that the

study results would be meaningful and relevant to informal caregivers.

The participants were invited to comment on what was important to them. The questions posed in the forum were informed by the caregiving literature and reflected the concepts of opportunity, freedom, and agency from the capability literature. The forum facilitated the emergence of unanticipated factors and accorded the caregivers an equal voice in the process of co-operative inquiry (Heron & Reason, 1997). The University Human Ethics Committee approved these procedures.

Analysis

The data were analysed using thematic analysis (Braun & Clarke, 2006), which has the flexibility to be adapted to suit a particular study. The first author read through the data, treating the participants' comments as descriptive, factual representations of their lives, and coding excerpts relating to the intersection between caregiving and paid work. Relevant excerpts were grouped thematically, using codes suggested by previous literature concerned with the intersection of informal eldercare and paid work. The codes and their relationship to the themes described in the findings were discussed and revised among the three authors.

Presentation of results

Excerpts have been reproduced as they were written, with the original spelling and grammatical constructions. This enables readers to evaluate the analysis and the evidence for the claims made; a collaborative reading of the "raw" data facilitates future discussion of the findings (Alkire, 2007). Some of the extracts reproduced below are a compilation of thematically similar comments from different postings by the same caregiver. Separate postings are joined by an ellipsis (...). This does not change the meaning of the excerpts included. The names referred to are pseudonyms.

Results and Discussion

The following discussion of results is structured around the consequences of deciding to provide informal eldercare for engaging in paid employment. The discussion focuses on trade-offs and constraints that affect caregivers' freedom to choose other valued capabilities and the resulting implications for their health. The findings from the first study are presented first, and then developed using an example from the second study.

Caring decisions

Emotional attachment informs the decision to provide informal care and also the caregivers' freedom to make choices that affect other capabilities such as employment options, living arrangements, leisure activities, and health. In this study, the participants regularly described work as something that they had given up because of caregiving. Their primary consideration was to make themselves available to care. Carol, a registered nurse, reduced her hours to care part-time for her mother who was in the terminal phase of cancer:

When she died I resigned from my work to care for my father who has Alzheimer's disease. He now lives with my husband & myself. We are his full time carers. While it was our choice we have struggled at times (caregiver for her father).

Similarly Rose gave up work to care for her mother:

The day she was discharged I got a call at work to come get her, she had told the staff I was living at her place and would give up work to look after her. So that's what I did (caregiver for her mother).

Jo was between jobs and wanted to do something "more meaningful than paper-shuffling" (female caregiver for her mother).

These caregivers relinquished paid employment in order to care for someone they cared about. In Rose's case the statement, "*So that's what I did*" suggests that the decision to care is self-evident. Their freedom to choose represents a dichotomy; either they remain employed or they provide unpaid informal care. Earlier in her posting, Rose describes how her mother cared for Rose's children while she worked. A shared history with her mother, and particularly feelings of wanting to give something back, influenced Rose's decision to become a caregiver to her mother, highlighting the relational nature of care and how this affects caregiver's choices regarding employment.

Employment and finances

Although these decisions are described as self-evident, they have considerable on-going effects in a caregiver's life. Dee discusses resigning from her full time job to provide support for elderly parents. Her father had recently passed away, but her mother still requires fulltime care. Dee says she no longer has "*financial peace of mind or freedom to do activities that I'd normally do*". After 9 months of caring for her mother, Jo's savings have run out and her sole income is a government benefit. Rose also relies on a government benefit, as a fulltime caregiver for her mother. Rose has been caring for her mother for the past 3 years. When her mother was discharged from hospital, Rose had just sold her own house and was staying with her mother temporarily. Now that Rose is a beneficiary and dependent upon state support, she can no longer own property because the payment she receives is insufficient to meet mortgage repayments. Rose's decision to become a caregiver to her mother is detrimental to her future financial security. Rose values being able to care for her mother, as much as her mother values receiving her care; however, the value that the state places on this arrangement is less than the minimum wage, which every adult worker is guaranteed. Rose's dependency, created because of her commitment to care for her mother,

renders her a “passive recipient of benefit” (Nussbaum, 2011, p.30). This not only stigmatises Rose but also undermines her dignity and fails to accord to her the respect she deserves as an individual and for her valuable contribution to family and society. The situation of these participants is not unusual, as research shows that informal caregivers often have fewer resources at their disposal to meet their needs (Bittman et al., 2007; Koerin et al., 2008).

Informal caregivers tend to reduce the hours they work, or give up employment altogether, due to the strain of combining both roles (Bittman et al., 2007; Lilly, Laporte, & Coyte, 2007). The social policy response to this has been to find ways to encourage and allow informal caregivers to remain in the workforce while providing care. However, Fine (2012) suggests that a better option would be to support informal caregivers to provide care, followed by assistance with re-employment when the need for care ceases. This solution could also address the financial struggle that caregivers face due to reduced income during the caregiving process. Income significantly decreases as caregiving continues (Bittman et al., 2007) and therefore “the damaging effects of sustained caring responsibilities are also likely to be cumulative” (Bittman et al., 2007, p. 264). Sarah describes cashing in her private superannuation to “*buy a decent car which catered for the special needs of my husband and also my dad.*” This kind of sacrifice illustrates how the effects of caregiving may continue well into retirement. In Sarah’s case, this is likely to have a double effect because women are more likely than men to spend their final years alone with fewer savings due to lower wages and caregiving commitments during their working life (Arnsberger, Lynch, & Li, 2012).

Finding a balance

Many caregivers in this study decided to reduce or leave employment because they were committed to providing care and struggled to manage caring and employment. When

they talked about choosing between work and caring, rather than reflecting on access to a range of options, “choices” were narrated in terms of being constrained, trading the capability to care against other valued capabilities. This has implications not only for financial security but also other capabilities that contribute to the participant’s overall wellbeing. For example, giving up work reduces a caregiver’s opportunities for social participation. Having given up work to care for her husband Sarah says:

I am already starting to feel a little trapped as it is difficult to take him out and when I do he just sits in the car so I go about whatever I am doing in a rush ... it takes me twice as long to get us both ready to go, it is worse than putting the grand- kids in their carseats ... lol (female caregiver for spouse and father).

Scott’s impression is that:

most carers become isolated in about every aspect of life. It is normal to feel resentful, angry, etc. in such situations. Carers sacrifice a lot of personal stuff to do a job that nobody wants to know too much about (male caregiver for his spouse).

Although Kath maintained her employment, she made several sacrifices to her social life so she could continue working:

I went through several stages. First I had to reorganise my life, and give up on few things sports, meeting with friends, as I had to continue working. We could not have survived if I had to quit my job (female caregiver for her spouse).

Remaining in employment can provide balance if it brings fulfilment and refuge. Being able to combine both roles brings a sense of satisfaction (Eldh & Carlsson, 2011). However, having the capability to combine caregiving with employment requires the

flexibility not only to juggle caregiving and work but also incorporate other valued activities into their lives, for example, leisure time to socialise and time to exercise. As Kath's story indicates, it is difficult for working caregivers to maintain a healthy work-life balance.

Because they are committed to providing care for a loved one, caregivers typically persist in their role until they themselves become unwell, or caregiving ends. Although trade-offs are a key part of informal caregivers' lives, caregiving is often the last capability to be forsaken; therefore, many caregivers describe the experience of caregiving as a time of putting their lives on hold. For example, "*I feel as if my life has been put on hold for the last year and half*" (female caregiver for her mother). Rather than attempting to balance the competing elements of their lives, caregivers prioritise caregiving and forgo other aspects of their lives until caregiving ends. Having to trade any valued aspect of life means making a "*tragic choice*" because whatever choice is made constrains a person's ability to flourish (Nussbaum, 2011, p. 37).

The caregivers' stories about trading the ability to work in paid employment to maintain caring highlight the extent to which caregivers will subsume their own needs and jeopardise their future financial and physical wellbeing in order to meet their commitment to care. To extend this finding, Study Two uses the findings from a second broader study about the role of emotions in informal caregivers' lives to develop an in-depth understanding of the complexities of combining work and care, in which the welfare of the person being cared for is important to the carer.

STUDY TWO: CIARA'S STORY

Method

Participants and procedure

Six informal caregivers from throughout New Zealand participated in Study Two. Four were recruited following the release of results from Study One, which contained details about the second study. The results were disseminated via the various organisations that had supported the first study and a media release. The participants initiated contact via email or a Freephone number. Each participant contributed up to six interviews. In total, 27 interviews were completed, with times ranging from 28 minutes to 1 hour 20 minutes. Interviews were scheduled around the participant's caregiving commitments. Originally, an interview each week for 6 weeks was planned; however, caregiving commitments meant rescheduling for some participants, so involvement with the study varied from 7 weeks up to several months. The participants were aged between 63 and 84; three were female and three were male; three were caring for a spouse and three for a parent. The care recipients' ages ranged from 64 to 92, with illnesses including heart disease, stroke, morbid obesity, Alzheimer's disease, and a rare terminal illness. The participants chose their own method of documenting their daily activities and feelings. Documentation methods included journal entries, emails, and photographs. This information provided a starting point for multiple semi-structured interviews between the first author and each participant. Once the researcher received each update, she contacted the participant and organised a telephone interview, which was recorded and transcribed prior to analysis. The University Human Ethics Committee approved these procedures.

Analysis

The data were analysed using narrative analysis. Narratives give an order and structure to events in ways that “give meaning to the experiences of the storyteller” (Stephens & Breheny, 2013, p. 14). Narrative analysis was chosen as a means to understand the complexity of caregiving informally for elders as a particular social relationship embedded within a social context. It is important to note that the excerpts presented here do not represent a once and for all story of informal caregiving, but rather a version of events co-produced with the interviewer. The first analytical step was to read through the transcripts, to identify the participant’s “personal stories” (Murray, 2000). Of the six participants, Ciara was the only caregiver who was engaged in paid work and eldercare at the time of the interviews. One participant had already sold his business to provide fulltime care for his wife; another had taken early retirement in order to care; two were retired when caregiving began; and the final caregiver had independent means so he no longer needed to work. Ciara contributed data suitable for a detailed analysis of the intersection between the dual roles of caregiving and working. Her story provides a fitting example on which to focus a narrative analysis of this topic. Ciara is an Irish pseudonym chosen by the participant because it is pronounced as carer. She is a 63-year-old co-resident caregiver for her 87-year-old father Errol (also a pseudonym) who initially suffered a stroke and now has on-going heart problems. Currently single, Ciara has three children and other family with varying degrees of involvement with Errol’s care. Ciara rented out her home when she moved in with Errol 7 years ago. She has been self-employed for 15 years and upon moving in with Errol she created an office space to work from home. This allows her greater flexibility to manage work and caregiving, which she feels she would be unable to do if she worked from an office in town.

Results and Discussion

The following narratives illustrate Ciara’s on-going struggle to reconcile self-

employment and eldercare. The stories resonate with the findings from the first study, particularly with regard to finances and health. They highlight the difficulties around time management; being able to mentally switch from one role to the other; and the emotional investment in eldercare. Ciara's aims for both roles are similar. It is important for her to always give her best and to finish what she sets out to do. This contributes to a sense of self-satisfaction and bolsters her sense of self as a responsible and competent person. In Ciara's own words, she is a "completer-finisher." However, her emotional attachment to her father and commitment to his care make it difficult for Ciara to combine both roles. She aspires to being a "good carer," which Pickard (2010) describes as a moral narrative widely employed in late modern society that refers to a traditional notion of caregiving. The good carer is caring, compassionate and empathic; someone who puts the needs of a care recipient ahead of his or her own needs. However, Ciara is simultaneously engaged in a contemporary, personal project as a capable businesswoman who derives satisfaction from running her own business. She has a responsibility to provide a professional service to her clients. Giving good service that meets her clients' needs not only enhances her reputation but also ensures repeat business that will contribute to her future financial security. The following excerpts illustrate the tensions of combining care and work as described by Ciara as she attempts to reconcile these aspects of her life.

The caring caregiver

Ciara situates her story of becoming a caregiver by describing the very close relationship her father enjoyed with Ciara's mother and her concern regarding Errol's ability to cope on his own. About 2 months after Ciara's mother's death, Errol had a stroke, followed by a heart attack. She recalls the moment when she broached the subject of his care:

*I remember asking him in Accident and Emergency when he was um, being checked over with his heart attack that um, you know, would he like to *inaudible speech* [come and live with me]. We had, I talked a bit about it with my sisters and him beforehand and he just smiled this big smile at me and I thought "Right."*

Ciara presents her decision to care for Errol as unfolding naturally from the set of circumstances. She presents herself as the most obvious candidate for the job, being single, the eldest, and having unconsciously adopted the role of family coordinator and organiser. She also holds a firm conviction that older people should be enabled to age-in-place, "*I do think if people can stay in their own homes it's best*" and therefore residential care is the very last option for Errol's care.

Ciara portrays the transition into caregiving as doing what is best for her father. The fact that she loves Errol is taken for granted. Being cognisant that his life may soon end, and having committed to being his caregiver, Ciara is determined to see it through until the end. Although she has moved beyond feeling that she must do everything possible to keep Errol alive, Ciara strives to provide the best care that she can, framed in terms of meeting Errol's needs, "*I feel hopeful that however long this lasts that I will look back on it with satisfaction knowing that Errol lived the last part of his life in a way that he wanted with care, respect and love.*" It is important to Ciara not to have regrets or feelings that she could have done more for Errol, which would undermine her narrative of being a good carer, and of her good care as a demonstration of being a capable person.

Throughout the 6 weeks of interviews, Ciara expressed concern over the quality of care she provides for Errol. In addition to providing the basic necessities of life, Ciara believes stimulation to be a vital part of good care. She says:

I like him to be able to go out and go to a movie with me or we go for a walk

somewhere or we visit friends or do something that's stimulating, go to a museum... and if he doesn't get that I think "Oh, gosh, he's been in the house all week" ... And if that happens for three weeks in a row, I sort of think "Oh, gosh, he's not getting enough stimulation" you know, those sort of things I think "Oh, the standard of care isn't very good."

Ciara's commitment to providing a good standard of care for Errol means that she attends to his needs at the expense of her own. This contributes to a sense of confinement and restriction in her life, as this journal entry indicates:

I have a little life. This weekend I've taken Errol to an 80th birthday party and I'm glad I went but it took virtually the whole day from 11am then home at 5.30 pm, make dinner, work in the office till bed time and now I'll have about 15 minutes to read before falling asleep ... Life is small in that the range of things I can do is very reduced. It makes me sad. Sometimes when I'm writing this journal I feel like a complainer about small things, sort of petty. And I don't like that small focus on such things. But it's inevitable as life here is a lot about the small things, cooking, cleaning, personal care, hats, scarves, gloves!

These comments suggest a tension between being happy to be at home in the role as caregiver, focusing on giving Errol the care he needs, and Ciara's desire to get on with her own life and pursue her own interests. Having just written about her "little life" she observes, "I went to 5 dance classes at the start of the year, only 1 hour a week, but I just haven't had the time to go back to it, and it was such fun and great exercise and my brain had to work differently. I loved it." Ciara acknowledges that time out from caregiving is beneficial for her wellbeing; however, she reports mostly feeling too tired to engage in these types of activities. Apart from occasional conversations with close friends, which she

treasures, Ciara has little respite from her caregiving to pursue activities for her own pleasure.

This notion of a “*little life*” also points to the different meanings of space and place. Ciara views home as a site for caregiving, with stimulating and leisure activities for both her and Errol understood as those activities that take place outside the home. Errol remaining inside the home is viewed as substandard care. This is further complicated by home also being a workspace for Ciara, which contributes to the “*littleness*” of her life. Ciara no longer encourages friends to come and visit because of the difficulties associated with sharing her home space with Errol, preferring instead to visit them in their own homes. Ciara also struggles with her recognition that this was originally Errol’s home. Ciara reports feeling left out of decision-making, especially with regard to interior decoration. Working from home provides flexibility for informal carers; however, Ciara points to some of the difficulties of managing care and work from home. When home is a site of contested meanings as in this example, combining work and care creates tensions for those living in the same space. These tensions point to the situated nature of care; the site of care produces opportunities and constraints and this recognition contributes a more nuanced understanding of the experiences of combining employment and eldercare.

The successful businesswoman

Ciara’s work as a self-employed business woman provides her main source of mental stimulation and social interaction. Ciara enjoys her work; she finds it interesting and challenging, and although it can be tiring she says, “*It’s good for me and you know, it’s good for my brain and good for my, for the relationships I form with people over time... and I love learning new things.*” She describes her work as “a blessing” because it provides a release and respite from caregiving; and she particularly likes the challenges it presents. When she has

done a job well, Ciara feels sense of satisfaction. The feedback she receives from clients confirms that she is able to function well as an intelligent person who has something to give to others in a professional capacity.

Despite the sense of fulfilment and satisfaction that she gets from work, Ciara experiences constant tension among her work obligations, her expectations for how she handles Errol's care, and what she can actually manage. This tension is particularly apparent as work provides a way for Ciara to move beyond the constrained boundaries of her *"little life."* In direct contrast to her previous comment about a little life she says, *"for me right now are the multiple commitments that are the biggest challenge, I'd like a simpler life."* These opposing comments are suggestive of ambivalence towards these dual roles. Ciara feels that her caregiving obligations mean that she is just *"sort of, treading water, sort of staying on the same spot"* to keep herself and the business afloat, and when caregiving diverts her attention away from work she has to:

sort of scramble like mad to catch up with my work and that's what's been giving me the heebie jeebies thinking "Oh goodness am I gonna, are people suddenly gonna say your work isn't good enough, Ciara and we can't you know, we you know, we can't employ you for things" ...

During a particularly stressful period with Errol, Ciara failed to keep an important appointment for work. Afterwards she said she felt like she was *"skating on thin ice, what a fiasco with my new client, I'm feeling rather shaky. Not good!"* She conceded that *"when I'm feeling so swamped I think 'Oh, I want to give it up it's all too much'."* Thus, although her work provides her with access to a wider world and intellectual stimulation which balances her caregiving responsibilities, at times Ciara feels that, *"all I want is an income without working so I could look after Errol without the pressure of my job."*

This story is at odds with Ciara the “*completer-finisher*” and in this comment Ciara directs her ambivalence towards her work situation. On the one hand, her work provides a welcome alternative to her life as a caregiver. On the other hand, when she feels overwhelmed with work and caregiving, she considers giving up work so that she can concentrate on caring for Errol. Through her management of these tensions, Ciara suggests that caregiving is her first priority. Although she expresses frustration with him and with the situation caregiving places her in, she has never considered giving up her role as his caregiver. However, being single, and self-employed, Ciara worries about her future financial security. Being aware that caregiving is a finite role, her only option is to find a way to juggle work with caregiving in order to maintain a viable business in the interim and generate income to support her retirement. Therefore, she has to keep the business running, while she attends to being a good carer.

The juggler

Ciara’s determination to carry on with both roles means that she moves back and forth between the roles, as she juggles their competing requirements. Thus, Ciara carves out a place for herself as “*the juggler*.” Sometimes this involves leaving Errol to fend for himself while she focuses on her work. She described one instance where she asked him to make his own tea, which Errol was happy to do, but he only managed a piece of dry bread and a tomato. Ciara felt guilty about this, admonishing herself for not providing “*good*” care for her father. However, “*neglecting*” Errol meant that she was able to fulfil her obligation to her client. On another occasion when her father suffered a serious bout of angina attacks while she was away for work, Ciara said she felt misunderstood and angry when her sister told her not to come rushing back for Errol’s sake. Her sister’s comment implied that returning would be Ciara’s immediate response, but Ciara said that even if she wanted to she could not just abandon her clients. Not

only did she have an obligation to them, she would have incurred a considerable financial penalty had she left. She said, *“I can’t just pike out and fly to Y. I have other obligations.”* However, she concludes her story with the comment, *“But there is such a feeling of being torn between so many responsibilities.”*

This story is typical of the comments in Ciara’s journal entries and interviews. Ciara desperately wants to do everything well. On the one hand, her love and compassion for Errol drives her commitment to give him the best care that she can; on the other, her sense of what is right and her desire to do her job well drives her commitment to her clients. Ciara values having the capability to care and to work, therefore she continues to try to find some kind of equilibrium. However, in this story she describes the difficulty of finding that balance:

I mean I’ve said there, you know, um, this idea of the desperate improvisation, and you know, sometimes it’s not desperate. I don’t want you to think it’s um, I’m feeling desperate all the time, I’m not but it is, it’s this incredible juggling act and I feel very torn between all the things that I’ve got to try and hold together.

Ciara often talks about her preoccupation with Errol’s health and how she is always thinking ahead to pre-empt any potential problems. Given this, Ciara finds it surprising that she can put thoughts of Errol aside when she is working. For example, following a particularly stressful time when Ciara was trying to remotely manage Errol’s care she commented, *“but I did do the work well which amazes me, you know, that I can actually focus on people when ten minutes before hand you know, I’m almost in tears.”* This indicates that it is possible to compartmentalise different aspects of life, and suggests that receiving appropriate support to combine the dual roles of work and caregiving could contribute to an overall sense of achievement and satisfaction rather than feelings of conflict and inadequacy.

The implications of juggling

In spite of exhortations from her family to take time for herself and to consider moving Errol into residential care, Ciara's solution for coping with the dual roles of caregiving and work are to *"put myself last, my kids tell me this and I know it's true."* She neglects her own health and other relationships, to the point where she has already taken a year off work because of exhaustion and burnout. The catalyst for time out was a back injury that resulted in her having to crawl around the house. She was told by the doctor and the neurosurgeon that *"I was too stressed and I was just holding myself so tensely, and um, that it popped."* Ciara now recognises that back strain and tinnitus are indicators that she is doing too much. She frequently refers to the connection between her physical health and her mental state, for example, *"Tinnitus was loud last night and it bothered me, it happens worse when I'm stressed and tired. I can't muster up much useful thinking tonight and feel a bit swamped by my emotions."*

Putting herself last means Ciara gives up *"things I love and sustain me."* Yet, she worries that she will be unable to look after Errol or work well if she does not look after herself. She knows that she needs to find a balance; however, she perceives that Errol's needs are greater than hers, *"so that's the whole thing of putting him first at the expense of myself."* Like many carers, Ciara focuses only on the need to look after herself as a strategy to sustain her as a good carer and a good worker, rather than to sustain her own wellbeing for its own sake.

Due to her caregiving and work commitments, Ciara cannot spontaneously choose to do something that is purely for her own enjoyment. Instead, these activities require planning and effort, which places further pressure on Ciara. Often, anything other than caregiving and work are put to one side or inadvertently overlooked. For example, Ciara

relates her anguish when she forgot to buy an Easter egg for her granddaughter. Celebrating Easter is important to Ciara's family, and giving her granddaughter an Easter egg signifies a meaningful exchange in their relationship. On Easter Sunday, when all the shops were closed she realised that she had been so busy prior to Easter, with work commitments and Errol's care that, *"the Easter egg thing had gone west really. So, I just, I just did feel like crying about that. Yeah, you know, this has happened two years in a row and I just got angry with myself."* In summary, Ciara's commitment to other relationships and to herself suffers from the strain of juggling multiple roles. When Ciara is unable to balance all the things in her life, she puts her own needs last. Ciara's overall narrative is about constrained choices that lead to trading one capability for another. In the first instance, Ciara gives up whatever is necessary in order to meet her commitment to being a caregiver for Errol. This devotion is based on her attachment to, and love for, her father. However, Ciara acknowledges that when her father is gone she will have to pick up the pieces of her own life and resume her former identities as Ciara the businesswoman, mother, grandmother, and perhaps partner, because only then will she have time to invest in a new relationship. She is fully aware that she must keep her business running out of financial necessity. However, she says, *"I don't see how any carer can possibly do a full time job! Or even part time and sometimes I, you know, I wish that I had some private income that I could just have enough money to live on and um, do the caring job and not have to stress at work."*

This comment highlights the seemingly unresolvable tensions associated with dual roles of being a caregiver and earning an income. This reflects the findings of both studies. Based on their love and attachment to the person being cared for, caregiving is the first priority of these carers. Being able to successfully combine work with caregiving depends on how well caregivers can juggle both roles. In some cases, like that of Rose in the first study, juggling dual roles is not an option, and work is forsaken in order to provide care. Other caregivers, such

as Ciara, continue to work, but because caregiving and work tend to be the least negotiable aspects of their lives, they trade leisure, social participation and relationships, and physical activities in order to prioritise caregiving and work commitments.

Conclusion

Together, these studies indicate a hierarchy of needs that caregivers must negotiate at the intersection of work and eldercare. The first priority is having the capability to care. It is a compassionate response to the plight of a frail elder; a particular kind of commitment borne of a shared social history and a personal relationship based on attachment (Kittay, 2013). Being able to work is the second priority. Depending on the particular circumstances, managing work with caregiving may involve a juggling act, or work may be forsaken altogether as previous studies have found (e.g. Barrett et al., 2014; Kim et al., 2013). Having the ability to maintain a healthy and balanced life is the caregivers' lowest priority. When life becomes too difficult to balance, informal caregivers appear prepared to give up, or place on hold, other capabilities they value and that would contribute to their own health and wellbeing.

The findings from the studies presented here support previous research regarding the problematic reconciliation of work and eldercare (e.g. Calvano, 2013; Eldh & Carlsson, 2011; Fast et al., 2013; Pavalko & Henderson, 2006), pointing to a conflict between two dominant social policies regarding workforce participation and informal eldercare. Engaging in both work and eldercare constrains caregivers' choices as they try to find a work-life balance. Many caregivers value the ability to work, because of financial necessity and because of the fulfilment it provides. In general, unpaid caregivers do not have the freedom to make decisions that promote their own health and enjoyment. Therefore, their physical, social, and emotional needs tend to be neglected, supporting Nussbaum's (2011) argument that needing to trade one

capability at the expense of another constrains human flourishing. Not having the freedom to choose other activities beyond eldercare and work has implications for informal caregivers' on-going physical and emotional health. This is an unjust situation (Fine, 2012). It is essential to recognise the impact that eldercare provision may have on the lives of a growing number of people with employment responsibilities. Although informal care has benefits for older people, and is a valued emotional relationship for the caregiver, the difficulties that such responsibilities to care create in people's lives need to be addressed in future social policy as well as focusing on the benefits such care offers in terms of population ageing.

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Final Reflections from the author

When I began this study I was concerned for the health of informal caregivers for older people and my reading of the literature was strongly influenced by the ‘burden’ discourse. Feeling frustrated that informal caregivers continued to experience stress and poor health, despite decades of research, I hoped that bringing a new perspective to the existing research, through the Capability Approach, might provide fresh insight and the potential for more effective interventions to support the informal caregivers.

The rationale for the online forum was to provide an opportunity for informal caregivers to deliberate about the kinds of things they considered important for their own health and to identify priorities and gaps in service provision that prevented the achievement of these goals. I could have approached the forum in similar way to Wolff and De Shalit’s (2007) study of disadvantage by using Nussbaum’s (2007) ten Central Human Capabilities (CHCs) to focus the interaction. This would have been a more pure form of democratic deliberation. However, I decided to take a more ‘grounded’ or bottom up approach working backwards from the caregivers contributions. While I may have been naïve in over-estimating the ‘political will’ of caregivers in New Zealand, the participants contributions were valuable and subsequent analysis highlighted an ethic care in terms of the relational nature of caregiving. At the same time, using Nussbaum’s list of CHCs as a template for the first phase of analysis, alerted me to the implications of emotions for caregiving in particular. Realising that emotions were intertwined with every other capability and the role they played in decision-making and trade-offs caused me to revise my focus on caregiving as burdensome. I began to question the efficacy of the burden concept, and interventions that focused on the demands of caregiving. Instead, I began to see a link between emotions and close relationships, which I thought may explain the partial uptake of existing interventions

aimed at improving informal caregivers' health.

The second study affirmed this, and drew me back to the ethic of care literature. This study in particular provided empirical examples of ethical care. In 'caring about' the people they were 'caring for' the participants mostly exhibited three of the four core elements identified by Tronto (1993): attentiveness, responsiveness, and what seemed to me to be competence. Although the participants appeared to be providing care in reciprocal relationships, interviews with the people being cared for would have enabled deeper insight into that aspect of caregiving. Overall, the results of both studies using the Capability framework highlighted the interdependent nature of caregiving and the importance of relationships.

On a more personal level, undertaking this research at the same time as providing care for my mother provided an opportunity for me to reflect upon the care she received from me and to compare my experiences with other caregivers. Providing care for my mother was not easy and as it became increasingly stressful I began to identify with the ambivalence cited in the literature and expressed by some of the participants in this study. After her death, with more time to reflect and more knowledge about ethical care, I realised I had not provided competent care. Yes, I had felt responsible for her care, and yes I had been attentive to her practical needs, but I was not responsive to her emotional needs and therefore I was unable to care for her in the way I think she wanted to be cared for. Over the course of her illness I 'lost' the mother I thought I knew and as I became more tired it was easier to just focus on practicalities and keep my visits brief. Upon reflection, I felt guilty and sad that my mother's final months were not what they could have been. In this sense I feel somewhat of a failure as a caregiver and I don't believe I am alone in this. My experience and the experiences of the study participants, although not necessarily the same

as mine, suggest that informal caregivers need a space in society where they can reflect upon such feelings, without being judged, and be supported through the ups and downs of the caregiving journey.

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Conclusion

The aim of this research was *to explore the health needs of informal caregivers* in the context of caring for older people. The first study aimed to determine *which capabilities are important for informal caregivers' health and wellbeing*. A second study arose from the findings of the first study, and explored *the role that emotions play in the everyday lives of informal caregivers for older people*. Both of these research questions were underpinned by a third question, related to the study methodology, that aimed to establish the potential of the Capability Approach (CA; Nussbaum, 2000, 2007, 2011; Sen 1980) as a theoretical framework that could generate new information about caring informally for older people.

A number of key findings emerged from this study that have implications for future theoretical understandings of informal caregiving for older people; for public policy regarding informal care for older people and for informal caregivers own understanding of providing care for older people. The findings were presented in six papers, and will be synthesised in the following section.

The first study employed a deliberative process of co-operative enquiry, via the Internet, that aimed to identify which capabilities informal caregivers for older people felt were important for their own health. The asynchronous, online format facilitated participants' textual self-disclosure of personal information, and less socially desirable responses, which led to a key finding that emotions play a significant role in the day-to-day experience of informal care provision. This was an unexpected finding, insofar as the expectation had been that participants would focus on the practical implications of care provision on caregivers' opportunities for self-care.

While these aspects of care were discussed in the forum, they were portrayed as

being embedded in existing relationships; most notably with the person being cared for, but also within wider family and institutional networks. Using Nussbaum's (2007) list of essential human capabilities as an a priori template to analyse the data highlighted that it was meaningless to consider these practical concerns in isolation, suggesting that the process of providing informal care for an older person was best understood in terms of its relational nature. This adds to the ethic of care literature, and is an important finding in that it provides empirical support for Nussbaum's (2007) inclusion of the capabilities for emotions, practical reason and affiliation as essential for living a decent human life. Additionally, the analysis revealed the interconnected nature of informal caregivers' capabilities and the implications of emotions with regard to caregivers' decision-making.

Emotional attachment to the person being cared for influenced the participants' freedom to choose what they were able to do, which included choosing to be a caregiver because they valued the opportunity to care for someone with whom they shared a long-term close relationship. Being able to carry out this role entailed having to make trade-offs with other capabilities, and putting their own lives on hold, which had the potential to compromise both their short and long-term wellbeing. The capability framework helped to shed more light on the reasons behind the sacrifices made by the caregivers, and thus provided some context for a dominant perspective in the caregiving literature that focuses on the burdens of caregiving in terms of negative emotional outcomes such as depression, stress and anxiety (e.g. Alpass et al., 2013; Fisher et al., 2011; Hirst, 2005; Pinguart & Sörenesen, 2003). The findings from this study suggested that the emotional pathway associated with informal caregiving is complex and that a more detailed analysis of caregiving as an interdependent relationship could offer some much needed balance to the attention on negative outcomes.

Therefore, a second, prospective study was undertaken, which focused on the role of

emotions in the day-to-day lives of informal caregivers. This qualitative study used a mixed-method approach that incorporated participatory principles insofar as participants chose their own method of data collection for the study. Narrative analysis of the data provided a nuanced appreciation of the role that emotions play in caregivers' attunement to the needs of the older people being cared for. All of the participants drew on idiosyncratic, or personal, narratives (Murray, 2000) to reveal caregiving identities. These narratives included being a competent, responsive caregiver; maintaining a positive attitude in demanding times; and being a manager and crusader on behalf of the person being cared for. A common narrative of acceptance was identified from the caregivers' personal stories, which was grounded in enduring personal histories and emotional attachment. These narratives also resonate with the ethics of care literature (see Barnes, 2012; Kittay, 2013; Noddings, 1984/2013; Tronto, 1993).

The findings from both phases of the research highlighted that these caregivers were committed to, and had accepted, their roles and that they were prepared to put the needs of the person being cared for before their own, which contradicts a dominant metanarrative that portrays individuals as autonomous, rational actors pursuing an ideal of individual achievement. The findings from the second study in particular, suggested that personal wellbeing was linked to the wellbeing of significant others and that providing care for someone in the context of a close relationship, was both valued by and morally important for the caregivers, thus affirming Noddings' (2013, p. 51) observation that "My very individuality is defined in a set of relations". These findings also reflect previous research that has found that caregivers feel more positive about their role when they believe that they have enhanced quality of life for the person being cared for (Schulz, 2013).

This relational aspect of caregiving is not a new discovery. But, what this study adds is an enriched understanding of how and why caregiving relationships impact caregivers'

achievement of other vital goals that contribute to their overall health. This becomes apparent in two ways. Firstly the act of giving care, which in itself is a vital goal, or capability, affects caregivers' opportunities to choose to do other things. This can result in a domino effect, for example, by decreasing the amount of time and money available to the caregiver, which in turn affects their opportunities for home ownership, exercise, socialising and so on. If one or more of those capabilities has to be sacrificed to achieve another valued capability then caregivers face a "tragic choice" (Nussbaum, 2000). Not being able to achieve one or more of these vital goals cannot help but affect caregivers' health.

Secondly, caregiving in itself is a vital goal, or capability. The caregivers in this study have demonstrated that providing care for a loved one makes them feel good and provides a sense of achievement. It is when they are not well supported that they have to give up other capabilities, juggle various roles and commitments, and sacrifice their own self-care. And this is where the 'messy' nature of capabilities as an evaluative tool comes to the fore. Earlier in the thesis I commented that capabilities were more like a tangled web than a linear list. This is supported in Venkatapuram's (2011; 2013) vision of health as a metacapability made up of a 'cluster' of capabilities. We can only appreciate this fully by looking at the overall picture, or social context, in this instance, for informal caregiving. As this study has demonstrated, the interconnected nature of capabilities, and the special role that emotions play in connecting capabilities, supports the ethic of care literature by highlighting the relational aspect of caregiving and the tensions associated with making choices based on an affectionate relationship or attachment to a significant other. While the CA can accommodate a relational ontology, its primary focus is the individual, nested within that tangled web of capabilities. Nussbaum (2000) contends that the goal of the CA is to produce capabilities for each and every person, and that capabilities belong to individual persons, rather than to groups. In this sense the CA diverges somewhat from an ethic of care approach, which I believe has meaningful

implications at a social policy level.

Implications for future theoretical and empirical research

This study adds to the somewhat limited empirical work using the CA, and more particularly Nussbaum's (2007) version of the CA. Many earlier studies using the CA are theory driven or use pre-existing data sets. The findings from this study provide strong support for using a capability approach to research the health needs of informal caregivers for older people. The capability framework directs researchers to gather rich information, resulting in a more nuanced appreciation of the complexities of caregiving, which has the potential to progress informal caregiving research. A capability perspective asks that researchers look at what caregivers consider is important in their lives and what they can do with their lives, given the extra demands associated with caregiving, and the decisions they need to make. Attending to the multidimensional nature of caregiving, in terms of what caregivers' are able to do, directs the spotlight onto the sacrifices or 'trade-offs' that caregivers make in order to continue caregiving. Given Venkatapuram's (2011; 2013) view of health as having the ability to achieve or exercise a cluster of basic human activities or capabilities, the constraints imposed by making these choices would appear to inhibit caregivers' ability to enjoy optimal health, or to flourish, which reflects previous research concerned with the negative outcomes of informal care provision.

On the other hand, the findings from this study indicate that the potential to flourish may be strongly associated with providing care for a loved one. Reflecting Fredrickson and Losada's (2005, p.678) definition of flourishing as having the opportunity for "goodness, generativity, growth, and resilience", these caregivers suggest that caregiving is valued and providing good care is a source of wellbeing, despite the associated burdens and stresses. In this sense, a feminist standpoint that underlines the value of a caring ethic dovetails

neatly with Nussbaum's (2000, 2007, 2011) version of the CA. Nussbaum's notion of capability commends the human expression of "moral sentiments such as benevolence, reciprocity and so forth that extend beyond a narrow motivation of individual advantage" (Comim, 2014, p.134). Nussbaum has moved beyond the concept of mutual advantage to a vision of humanity whereby individuals express a strong commitment to the good of others. Thus, an ethic of care underpins Nussbaum's CA, which has the potential to fruitfully investigate what informal caregivers value most about providing care and the intricacies of their decision-making.

The findings from this study suggest that refocusing informal caregiving research using Nussbaum's (2000, 2007, 2011) CA would direct discussion away from the burdens associated with the practicalities of caregiving, and towards caregiving as a valued activity that contributes to human wellbeing. In particular, understanding that providing informal care for a significant 'other' is a valued capability that caregivers are not prepared to forgo in order to achieve individually oriented goals is important. This merits further investigation, with caregivers in different contexts. For example the capability lens to be focused on caregiving for children, siblings, people with disabilities, friends and neighbours, or indeed in any situation where care is given.

Implications for policy

International figures consistently indicate that as much as 80 percent of long-term care for older people is provided in their own homes by informal caregivers. This reflects the default option for policy makers, and care in the community by the community (Heaton, 1999) is likely to continue. The provision of care in the community takes for granted informal caregivers availability and willingness to provide care based on kinship ties and feelings of responsibility for the person in need of care. The findings from this research suggest that this

is a reasonable assumption; however, the findings also indicate that informal care provision can be problematic, in terms of caregivers' propensity to neglect their own health, as they put the needs of the person they are caring for ahead of their own.

Despite widespread recognition that informal caregivers need support for their role, interventions to provide support generally have a modest effect on caregivers wellbeing (Pinquart & Sorensen, 2002), including community-based respite (Shaw et al., 2009). Previous research has suggested that this may be due to a mismatch between services on offer and caregivers' needs (e.g. Nolan et al., 2003; Zarit & Leitsch, 2001). From a capability perspective, providing more resources is unlikely to be an effective solution to the issue of caregiver support, if caregivers are unable or reluctant to use them. The participants' narratives indicate a caring ethic, evidenced in their commitment to provide attentive and competent care, and their willingness to put their own needs and plans on hold. Additionally, the caregivers' decision making was explained in terms of relational autonomy. This has important implications for the way in which supportive interventions might be planned and offered to caregivers.

For example, respite care is less likely to be accepted or utilised if caregivers are unwilling to leave the person they care for with someone whom they perceive may offer a lesser standard of care. Several of the participants in this study indicated that the care they provided was the 'best' care, because it was based on an intimate knowledge of the needs and wishes of the person they were caring for. Moreover, the caregivers talked about not being able to switch off mentally while they were away from the person being cared for and feeling like they had not had a break after caregiving resumed. In this respect, respite care may not be an effective option for some caregivers. Additionally, caregivers have limited time available to spend sourcing help because they are engrossed in the care of a loved one; or

they may not look for help because they do consider that they belong to the collective group labelled as 'caregivers'. Rather, they view the care that they are providing as nothing other than what would normally be expected in a close relationship (Walker, 1995).

In contrast to a uniform approach to support interventions for caregivers, Blum and Sherman (2010) suggest tailoring interventions to fit particular circumstances. This would involve collecting detailed information about the particular dynamics and context for care (Nolan et al., 1996, 2006) for each individual. Such assessments would need to be ongoing as the caregiving trajectory changes, particularly at important transition points (Schulz, 2012). The methodology employed in this study suggests a possible way forward for social policy aimed at supporting informal caregivers, which could accommodate these suggestions.

Acknowledging that interventions, such as respite care, take the caregiver away from the person being cared for, thus straining the bond that they share, points to the potential for providing support in the home. Participants in this study discussed the benefits of Internet chat groups as a way of taking time out, while remaining 'present' for the person they were caring for. These groups were not necessarily associated with caregiving, but did provide the opportunity for anonymous, supportive conversation and advice between group members.

Similarly, participants commented on the therapeutic effect of narrative reflexivity, through being able to express feelings associated with caregiving. Incorporating the immediacy and anonymity of the Internet with the natural propensity for storytelling, suggests promising avenues for development in social policy aimed at improving the wellbeing of informal caregivers for older people. For example, digital technologies would provide a cost effective way of reaching caregivers in their own homes to provide education, support and social interaction. Moreover, caregivers could be involved as collaborators, as lay educators sharing practical experience, and in designing appropriate interventions. This would address the problem of treating caregivers as resources and passive beneficiaries of policy, both of

which are concerning from a capability point of view.

Although Nussbaum's (2007) list of central human capabilities has been developed for deployment at policy level, she also advocates for citizens to play a fundamental role in constructing just societies (Comim, 2014). Additionally, Nussbaum argues that moral sentiments such as sympathy, benevolence, justice, respect, understanding and compassion should not be assumed (Nussbaum, 2000). Rather, she believes that moral sentiments can be constructed, particularly through education within the family in the home. However these principles require societal support; therefore work needs to be done to promote and value care for its intrinsic contribution to the fabric of society, not just as a solution to the problem caring for increasing numbers of older people.

Future research

This was an exploratory study that tested the efficacy of the CA to offer a different way of understanding the health needs of informal caregivers for older people. The study has yielded some interesting results, and also raised further questions, which suggest new avenues for future research. For example, further research is required into informal caregivers' decision-making at important transition points in the caregiving trajectory. These transition points include entry into caregiving, entry into residential care, moving into the palliative phase, and the cessation of care. Another topic for research related to this might include examining informal caregivers' and care receivers' resistance to residential care, which would involve revisiting formal care provision within residential care facilities. This research would benefit from using longitudinal, participatory and narrative methodologies that allow for both the daily aspects of care and a broader narrative of caregiving to be represented. Further research is also required to more fully understand the difficulties around integrating self-care with caring for another. It is imperative that informal caregivers' are recognised as

individuals who also need care, as opposed to being a resource for providing care; and therefore informal caregivers must have the capability to provide care without compromising their own self-care. It is clear that research is urgently required that would improve understanding of the value and limitations of existing support services for informal caregivers. For example, an in depth exploration of how informal caregivers' need for support is identified and how support is offered to caregivers would be valuable. Relatedly, informal caregiving research would benefit from a focused study of respite care from the viewpoint of those who find it useful. This could incorporate the perspectives of those who utilise respite care, as well as those who provide it.

Limitations

This study has generated new insights into the health and wellbeing of informal caregivers for older people. It has raised some interesting findings in relation to the role that emotions play in caregivers' decision making, particularly with regard to trading capabilities and forgoing opportunities for self-care in order to continue informal care provision. The findings suggest that support for informal caregivers health might benefit from using Venkatapuram's (2011; 2013) theory of health. However, as with all research, the study has a number of limitations that must be considered when interpreting the results.

The first limitation relates to recruitment and participant characteristics and raises several issues. Firstly, despite attempts to attract as many caregivers from New Zealand as possible into the first study, the sample remained relatively small. Secondly, although every effort was made to involve a diverse range of caregivers, it is possible that because participants self-selected they came into the study with a particular view of caregiving. For example, they may have been politically motivated to join the study because they wanted to help improve support for informal caregivers. Thirdly, the study included only those people who actively identify as caregivers. These people may have a qualitatively different view of caregiving compared to those who do not consider that they are doing anything other than tending to the

needs of someone with whom they share a long-term relationship (Walker, 1995). Other researchers have noted the difficulty in engaging informal caregivers in research because family members, and particularly spouses, tend not to self-identify as informal caregivers (Dobrof & Ebenstein, 2003; Fredriksen-Goldberg & Hooyman, 2007). Finally, the majority of participants were in the young-old age range, or under 75 years of age. The age of informal caregivers will likely increase, pointing to the potential for research to be undertaken with the older age-groups in order to be able to provide the best possible support for older caregivers.

The decision not to collect demographic information in Study One and only partial demographic details in the second study may be considered a limitation. However, there have been a multitude of informal caregiving studies that have focused on particular characteristics in particular contexts and this study was a deliberate attempt to take a broad-brush, exploratory approach to informal caregivers' health in general. In saying that, however, there is definitely the potential for further research in particular areas, for example by focusing on the health needs of different age and ethnic groups of informal caregivers.

A second limitation relates to the failure to generate a list of capabilities, relative to the context of informal caregiving for older people, which was the aim of the online forum. This highlights both the pitfalls and benefits of using participatory principles in research. Although the participants were invited to deliberate and interact to collectively produce a capability list, interaction was limited and instead, the participants took the opportunity to tell stories about their experience of caregiving. A valuable lesson learned was that participatory research methods need to be flexible and able to evolve to meet the needs of the participants. Although the forum did not work in the way that was planned, the online format generated rich contextual data, which moved the overall study in a new and unanticipated direction. The results from the forum led to Study Two, which in turn

influenced a shift from Sen's version of the CA to Nussbaum's version, which was more suited to the study of caregiving. Specifically, the study moved away from a focus on capability as an evaluative tool to a qualitative focus on Nussbaum's capabilities as a rich source of information that provided a deeper understanding of informal caregiving. This highlighted the significance of a caring ethic in the lives of these caregivers.

A final limitation of this study is the relatively homogenous nature of the findings in that all caregivers told a story of being good citizens who valued the opportunity to provide competent, attentive care and derived meaning from doing so. The feminist literature related to caregiving indicates that this is not always the case (e.g. Barnes, 2012; Tronto, 1993). Care is not always good, as attested to by stories of elder abuse; and not everybody values the opportunity to provide care (see also Barnes, 2012). Additionally, caring for someone you care about does not necessarily guarantee the provision of good care (Nolan, 2001). As Barnes argues 'care' is a contested term and careful attention needs to be given to its use. This invites the possibility for further narrative research with people who have chosen not to provide care for a significant other. Their stories may provide insight into different kinds of complexity in organising relations of care. Caution should be exercised in interpreting the findings from this study, because they represent the care given by a particular group of people and cannot be construed as applying to all informal caregivers for older people.

Conclusion

In contrast to previous research that focuses on the negative health outcomes of providing informal care, the findings presented here indicate that providing care for a significant other is a valued capability, which can be beneficial for caregivers' own wellbeing. However, informal caregiving can be problematic, as indicated by the participants' sometimes ambivalent experiences of caregiving. Emotions were found to play an important role in caregiving, affecting decision making, contributing to trade-offs and

caregivers neglecting their own self-care. In general, talk about caregiving reflected attentiveness, commitment, compassion and acceptance, suggesting that an ethic of care underpinned the caregivers' approach to providing competent care, and that the caregivers' wellbeing was inextricably linked with the wellbeing of the person being cared for. As well as the relational aspect of providing care the CA reminds us that we must remain mindful of the uniqueness of each caring relationship and the needs of the individuals providing care at the heart of these relationships. These findings have important implications for the design and implementation of interventions aimed at supporting the health of informal caregivers for older people.

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Appendices

Appendix A:

Nussbaum's List of Central Human Capabilities

The basic idea is that with regard to each of these, we can argue, by imagining a life without the capability in question, that such a life is not a life worthy of human dignity.

Martha C. Nussbaum.

- 1. Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
- 2. Bodily Health.** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
- 3. Bodily Integrity.** Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
- 4. Senses, Imagination, and Thought.**

Being able to use the senses, to imagine, think, and reason-and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use

imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid nonbeneficial pain.

5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)

7. Affiliation

a) Being able to live with and toward others, to recognize 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, and also protecting the freedom of assembly and political speech.)

b) Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of nondiscrimination on the basis of race, sex,

sexual orientation, ethnicity, caste, religion, national origin.

8. Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. Play. Being able to laugh, to play, to enjoy recreational activities.

10. Control over One's Environment.

a) Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

b) Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

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Appendix B

Printed on Massey University Letterhead

**CARERS' VOICES:
A COLLABORATIVE ONLINE STUDY OF WELLBEING
INFORMATION SHEET**

Introduction

Are you an unpaid carer for an older person living in the community? If so, I would like to invite you to take part in this study about carers' wellbeing.

My name is Barbara Horrell and I am a PhD candidate from the School of Psychology at Massey University. My supervisors are Associate Professor Christine Stephens and Dr Mary Breheny, both from the School of Psychology, Massey University.

Why is the research being done?

The purpose of this study is to find out about the kinds of things that carers need, or value, to maintain their health and wellbeing while caring for older people. I would like to draw on your experience and insight to help me to create a list of what carers need to enhance their wellbeing. I will use this list to evaluate the wellbeing of carers in a future in-depth study of the caregiving process, which will also be part of my PhD thesis. The overall aim of both projects is to investigate the needs of carers and to contribute to improved levels of wellbeing for carers of older people living in the community.

Who can take part in the study?

Anyone who is providing unpaid community care for someone who is aged over 65 is eligible to take part in the study. The details about the project have been advertised on various websites throughout New Zealand. These websites are either specifically for caregivers or of potential interest to carers of someone with a particular illness. The advertisements contain a link to the carers' internet forum website. There is no limit to the number of participants who can take part.

How do I participate?

If you wish to take part, you are invited to join the forum on this website. Before you can access the forum you will be asked to enter a valid email address.

The forum will take place over four weeks. For the first three weeks I will post a series of questions and comments related to specific topics on the website. You will be able to respond, and interact with me and other carers via these discussion threads. During these three weeks everyone will have the opportunity to submit new ideas or topics that they would like to see discussed. I will collate these to form the topic for our final week's discussion.

The forum has been set up for research purposes only. Although members may be supportive of each other, this is not a support group. I have provided links to other websites with carer support groups on the USEFUL LINKS page on this website if you require additional support as a carer.

Participation in the forum assumes that you have read this Information Sheet, as well as the information under the PRIVACY and NETIQUETTE headings, and implies that you have consented to take part in the discussions.

If there is anything you do not understand, or if you have any questions, please contact me by telephone, **0800 437 136** or email **barbarahorrell@gmail.com**

What will happen to the information from the discussions?

During the month that the forum is running the site will be backed up by the hosting service. At its conclusion, the forum page will expire and will no longer be accessible. All of the information from the forum will be downloaded by the hosting service and erased from the website. When I have created a summary of that information, I will post these results to the home page of this website for anyone to read. These results will remain accessible on the website for several months after the end of the forum before it expires completely.

Participants in the forum will be asked not to identify or give details about the person being cared for.

Any written data from the website will be stored in a secure location and will only be able to be accessed by myself or my supervisors. No names will be linked to the stored results. Data will remain stored for 5 years and then disposed of in a safe manner.

At the conclusion of the project, a summary of the results and associated reports will be available on the websites that advertised the study. The results may also be published as part of my thesis, at conferences and in scientific journals. Your name will not be used in any publications.

Your rights

You are under no obligation to accept this invitation. If you decide to participate you have the right to:

- decline to answer any particular question and to decline to participate in any thread posted on the discussion board
- withdraw from the study before the month is up. However, any contributions you may have made will remain on the discussion board
- ask questions about the study at any time during participation, either through the forum or directly to me by email or 0800 number
- contribute to the discussion on the understanding that your name will not be used and your email address will not be shared. You may choose your own pseudonym
- be given access to a summary of the project findings when it is concluded

Ethical Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/67 If you have any concerns about the conduct of this research, please contact Dr Karl Pajo, Chair, Massey University Human Ethics Committee: Southern B, telephone 04 801 5799 x 6929, email humanethicsouthb@massey.ac.nz

Further information

If you have any questions or would like further information at any time please contact either myself or my supervisors:

Barbara Horrell	Dr Christine Stephens	Dr Mary Breheny
PhD candidate	Associate Professor	Research Officer
Massey University	Massey University	Massey University
████████████████████	C.V.Stephens@massey.ac.nz	M.R.Breheny@massey.ac.nz
██████████	Phone: 06 350 5799 x 2081	Phone: 06 356 9099 x 2069

Thank you for taking the time to consider this invitation. I would greatly appreciate your collaboration in this study.

Yours sincerely,

Barbara Horrell

Appendix C

Letter to Support Organisations

Carers' Wellbeing in the Context of Ageing-In-Place

Who am I?

My name is *Barbara Horrell* and I am a PhD candidate from the School of Psychology at Massey University. I am interested in studying the wellbeing of people who are caring for older people in the community.

Why am I contacting you?

I am contacting you to ask for your support for this project.

What is the study about?

The purpose of this study is to find out about the kinds of things that carers need, or value, to maintain their health and wellbeing while caring for older people. Caring for carers has become more widely researched in recent years, however few studies have included carers in the early stages of the research design. I value the experience that carers have and believe that their insight can help me to design a more useful study. Therefore, I want to invite them to join me in this initial phase of the research to identify issues and concerns that might be important for their wellbeing.

What is the procedure for the study?

The initial stage will be an internet discussion group, moderated by myself, which will enable carers nationwide to interact with me, and with each other, to discuss the things that they feel are important for their own wellbeing. I will introduce topics, in the form of discussion threads, to start the ball rolling over the first 3 weeks. In the fourth week, carers will be invited to introduce anything that has not already been covered. After one month, I will collate the responses and then feed back to the participants with a list of items that have been

collaboratively identified as important. This part of the study will enable carers to have a collective voice about issues that are relevant to them. I will also provide feedback to you as a support organization.

This list will guide the second stage of the study. I am hopeful that this stage will evolve from suggestions made through the discussion group, based on what the participants think is the best thing to do with the information we have collectively created. One thought that I have is to keep in contact with up to six carers, using private blogs, over a period of up to 3 months. The purpose of this stage would be to follow the caring process, in depth, to gain some understanding of how it changes over time, and to see how well the previously identified issues might work as a measure to evaluate carers' wellbeing. However, the participants may come up with other and perhaps more practical ideas. The project will have the flexibility to adapt as it progresses.

The overall aims of the study are to provide a unified voice for New Zealand carers, to increase awareness of the process of caregiving, to inform social policy and to enhance the wellbeing of carers of older people living in the community.

Who will be involved in the research?

Anyone who cares for someone aged 65+ and who is still living in the community will be eligible to take part. Participants will need access to a computer, at least on a weekly basis.

How can you help?

I am hopeful that you will support the project by telling people about the study and advertising it through your website. Every effort has been made to ensure confidentiality for the participants taking part.

Contact details:

I may be contacted by email at *barbarahorrell@gmail.com* or by telephone, 0800 437136. Please do not hesitate to contact either of my supervisors, listed below, if you have any queries or concerns about the project:

Dr Christine Stephens

Associate Professor

School of Psychology

Massey University

Private Bag 11 222

Palmerston North

Phone: 06 350 5799 extn 2081

Fax: 06 350 5673

Email: C.V.Stephens@massey.ac.nz

Dr Mary Breheny

Research Officer

School of Psychology

Massey University

Private Bag 11 222

Palmerston North

Phone: 06 356 9099 extn 2069

Fax: 06 350 5673

Email: M.R.Breheny@massey.ac.nz

Thank you for taking the time to read this information.

Yours sincerely

Barbara Horrell

Appendix D

carersvoicesnz - Summary of results

This study examined the experience of providing informal care for older people.

Informal carers from around New Zealand were invited to contribute to an online forum, carersvoicesnz, to discuss their experience of caring for elders. Over three months, 60 carers responded to my questions about caring and introduced their own topics for discussion. The carers' stories reflect a diverse range of experiences encompassing caring for spouses, parents, grandparents and non-family members; living with the person being cared for, providing moral support, running errands, and caring at a distance; and caring for people with different illnesses, including chronic conditions associated with ageing, cancer, stroke, Parkinson's and Alzheimer's.

When the forum closed I studied the participants' comments, focussing in particular on their capabilities, or what they are able to be and do. The carers talked about similar things, such as giving up paid employment, having access to timely and appropriate information, having time for themselves, and spending time with friends. They discussed being safe from abuse, wanting their own space, and being respected for their expertise and knowledge about the person being cared for. Their comments were mostly framed in terms of losing or not having certain capabilities, suggesting that being able to care entails trade-offs with other valued activities.

Decision-making associated with trade-offs appears related to the complex emotions characteristic of caring relationships. On the one hand, the carers describe how emotional attachment influences the decision to care, generating positive feelings such as happiness, satisfaction, and emotional fulfilment, which indicates that they value caring for others. On the other hand, putting others' needs ahead of their own affects carers' freedom to be able to do the things that they would like or need to do for themselves. As a result, the carers describe changing relationships with the person being cared for, as well as other family members, as the caring process unfolds. Feelings of frustration, resentment, grief, longing,

and anger are accompanied by feelings of guilt, suggesting that they consider some emotions more acceptable than others.

The experience of both positive and negative emotions highlights the ambivalence and tension inherent in caring. It also highlights the difficulties associated with managing care alongside other everyday activities. The comment “one day my life will go on” suggests that being able to care is not naturally and easily incorporated into daily life. Providing informal care therefore becomes an extra-ordinary activity requiring careful management in order to maintain one’s own wellbeing.

Based on these findings, the next stage of the research will explore in more depth the feelings that informal carers for older people experience in their everyday lives. Over a period of several weeks, I will talk with carers about their day-to-day experiences. They will be able to choose a way to document what they do and how they feel, which may include keeping a diary, taking photos, making voice recordings or a combination of any of these. This will be used as a starting point for our discussions. It is hoped that the information will enhance our knowledge of informal care and lead to more appropriate support for people caring informally for elders.

For further information about this, or the future study, please contact Barbara Horrell on 0800 437136 or email barbarahorrell@gmail.com.

Appendix E

Printed on Massey University Letterhead

Caring for Elders in the Community:

Focussing on Feelings

INFORMATION SHEET

My name is Barbara Horrell, and I am a PhD student from the School of Psychology at Massey University. My supervisors are Dr. Christine Stephens from the School of Psychology, and Dr. Mary Breheny from the School of Health and Social Services, Massey University. I am interested in studying the wellbeing of people who are caring for elders in the community. This stems from my own caring experience and involvement with elders in my community.

Why am I contacting you?

I am contacting you to invite you to take part in research about the wellbeing of informal carers for elders. This study will explore the range of feelings you experience while caring for someone living at home. This will assist us to better understand community care and work towards providing appropriate support for carers.

Who will be involved in the research?

People will be eligible to participate if they are caring, without pay or formal support, for someone in the community who is aged 65, or above. Participants will be given a koha, or gift, in appreciation of their time spent helping with the study.

How can you help?

If you decide to take part in the study you will be helping me to collect information about caring for elders. I have already completed the first phase of my PhD project, which looked at how carers keep themselves well. The results of that study suggest that carers' feelings are very important. I would like to examine this more closely.

You can help by documenting what it is like to be the carer for an older person. You will be able to choose how you do this. For example, you may like to take photos, keep a daily diary, make voice recordings, write poetry, or compose a song. I will give you any equipment and guidance you need, and we will meet weekly for no more than six weeks to discuss the material you have collected, or created, and decide what it means. How you document your life as a carer, how much time you commit to the project, and how and where we meet for our follow-up discussions, or interviews, will all be discussed at our first meeting.

Our follow-up discussions will be recorded and then be transcribed by a typist who will sign a confidentiality agreement. You will be able to read the transcripts and make any changes before I use this material in my thesis.

My role in this project is one of co-researcher. I am not a health practitioner and so am not in a position to provide any health advice, counselling or ongoing support after the project has been completed. However you may find any of the following organisations helpful:

Carers New Zealand	0800 777 797	www.carers.net.nz
Alzheimer's New Zealand	0800 004 001	www.alzheimers.org.nz
Cancer Society of New Zealand	0800 226 237	www.cancernz.org.nz
Parkinson's New Zealand	0800 473 4636	www.parkinsons.org.nz
The Stroke Foundation NZ	0800 78 76 53	www.stroke.org.nz
Age Concern	Various local numbers	www.ageconcern.org.nz
Citizens Advice Bureau	0800 367 222	

Depression Helpline	0800 111 757
Health and Disability Advocates	0800 555 050
Work and Income	0800 559 009

What will happen to the information you contribute?

Your contribution to the project will be used for my PhD thesis. You may keep the data you collect (photos, diary etc.) if you wish. I will make a copy of the material you wish to keep, for my own records. You will be offered a copy of the edited recording transcripts, and at the end of the project I will provide you with a summary of the research findings.

Results from the study may be presented at conferences and included in scientific publications. A summary of the results will be sent to the organisations that have an interest in informal care and that have supported the study from the beginning.

All of the data you contribute, including transcripts, will be safely stored while I am working on the project, and be accessible only to myself or my supervisors. Data will be stored for 5 years after the project is completed and then disposed of in a safe manner.

Your rights as a participant:

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time before our meetings are completed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;

- ask for the recorder to be turned off at any time during the interviews.

Contact details:

If you have any questions, or would like more information about the project, please do not hesitate to contact me, Barbara Horrell, by telephone 0800 437136 or email barbarahorrell@gmail.com or my supervisors:

Dr Christine Stephens

Associate Professor

School of Psychology

Massey University

C.V.Stephens@massey.ac.nz

Dr Mary Breheny

Senior Lecturer

School of Health and Social Services

Massey University

M.R.Breheny@massey.ac.nz

Thank you for taking the time to consider this information. I will contact you to see if you would like to take part in the study.

Yours sincerely,

Barbara Horrell

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 12/19. If you have any concerns about the conduct of the research, please contact Dr Nathan Matthews, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 350 5799 x 8729, email humanethicsouthb@massey.ac.nz

Appendix F

Printed on Massey University Letterhead

Caring for Elders in the Community:

Focussing on Feelings

PHOTOVOICE INFORMATION SHEET

Hello, my name is Barbara Horrell, and I am a PhD student from the School of Psychology at Massey University. My supervisors are Dr. Christine Stephens from the School of Psychology, and Dr. Mary Breheny from the School of Health and Social Services, Massey University. I am interested in studying the wellbeing of people who are caring for elders in the community. This stems from my own caring experience and involvement with elders in my community.

I am currently running a study that is concerned with carers' feelings. This will assist us to better understand the experience of caring for elders and work towards providing appropriate support for carers. You will have been given this information sheet by someone who is taking part in this study. They have chosen the Photovoice option as a way of documenting their life as a carer for an older person.

Photovoice involves using a camera to record a person's daily activities. In this study, participants are using photos to document their experience of caring. When the photos are developed, the person who gave you this information will meet with me and together we will talk about what the photos might mean to them. This information may then be included in my study and later presented at conferences or published in scientific journals. I will not use photos that may identify anyone in any publication or at any conference.

We are asking for your consent to be included in the photos. You are under no obligation to say yes. If you agree, there is a separate consent form that you can sign, which I will keep in a safe place. Your name will not be linked with any of the photos or information that arises from them being taken.

Contact details:

If you have any questions, or would like more information about the project, please do not hesitate to contact me, Barbara Horrell, by telephone 0800 437136 or email barbarahorrell@gmail.com, or my supervisors:

Dr Christine Stephens

Associate Professor

School of Psychology

Massey University

C.V.Stephens@massey.ac.nz

Dr Mary Breheny

Senior Lecturer

School of Health and Social Services

Massey University

M.R.Breheny@massey.ac.nz

Yours sincerely,

Barbara Horrell

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 12/19. If you have any concerns about the conduct of the research, please contact Dr Nathan Matthews, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 350 5799, x 8729, email humanethicsouthb@massey.ac.nz.

Appendix G

Screenshots of the carersvoicesnz Forum

