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An investigation into the psychological impact of informal aged care: The lived experience of older female informal aged carers

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An Investigation into the Psychological Impact of Informal Aged Care: The Lived

Experience of Older Female Informal Aged Carers

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Abstract

It has been estimated that 196,000 (38%) informal carers in Australia are aged over 65 years, with the majority of these carers providing care to someone in their own age group. In particular, it is women who have been providing most informal care. Recognition of this has highlighted women's needs for psychological support in their caregiving roles. However, research into women's experiences of this phenomenon is scarce. The present study aimed to explore the lived experiences of women in this context, asking the question "what are the perceived psychological impacts of aged care on older women who are informal carers?" Semi-structured interviews were conducted with ten female informal aged carers who were between the ages of 65 and 76 years. Using an interpretative phenomenological approach, three main themes have emerged: socio-cultural; spiritual; and personal. The interviews revealed that deleterious caregiving consequences originated from issues of loss, entrapment, obligation, social isolation, guilt, and uncertainty. Positive caregiving consequences encompassed finding a sense of meaning in life through the caregiving experience. The findings conclude that health care providers can take a lead role in working with this group in three ways: Firstly, in identifying circumstances under which negative caregiving outcomes might be more pronounced; secondly, intervening with individualised care strategies to meet carers' needs, and finally; improving carers' access to mental health services. These may provide such supports so that carers do not feel alone and isolated in their roles. Future research is required to assess gaps in the understanding of carers' experiences of informal aged care across a variety of contexts, and to improve service provision in this area.

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Researcher: Emma Stein

Supervisor: Dr. Eyal Gringart

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Signed: Emma Stein

Dated: 27 October 2014

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achievement possible.

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An Investigation into the Psychological Impact of Informal Aged Care: The Lived

Experience of Older Female Informal Aged Carers

Australia, like other Western countries, is in the midst of a demographic transition of

population ageing. To illustrate the magnitude, the Australian Bureau of Statistics (2012b)

estimates that the proportion of people aged 65 years and over is expected to rise from 3.2

million people (14% of the population) in 2012, to 11.1 million (24.5%) by 2061. Coinciding

with this transition is unprecedented pressure on health and social support care systems to

weather increasing rates of chronic illness, as well as issues related to normative ageing. In

response to this, health policies have promoted support for self-management amongst patients

(Essue et al., 2010). In practice, this often implicates those providing primary, unpaid, and

ongoing home-based care (informal) to dependent family or friends who are ageing and in

need of intensive support (Cosper & Moyer, 2013).

Informal carers represent an important source of support for other older adults. Carers

assist with long-term, self-managed, and home-based care systems, help maintain quality of

life and functional ability in the care recipient, and reduce societal costs by decreasing the

need for care recipient institutionalisation (Cassie & Sanders, 2008; Mittelman, Haley, Clay,

& Roth, 2006). In fact, based on an assumed hourly wage of $25.01, the annual cost of

replacing formal assistance with that contributed by informal carers in Australia, has been

estimated at over $30 billion (Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2010).

One cohort who has been over-represented in the informal carer population is older

adults over 65 years. In particular, it is women who have been providing the substantial

proportion of informal care (Ranmuthugala, Nepal, & Brown, 2009). The ageing carer

population requires immediate attention, as in 2012, 196,000 (38%) primary carers in

Australia were aged over 65 years. Of these older carers, four out of five (82%) provided care

to someone in their own age group (Australian Bureau of Statistics, 2012a).The prevalence of

clinical psychiatric disorders in older informal carers is substantial. Despite this, few psychologists in Australia have the training and expertise to work with this demographic. Thus, there is likely to be inadequate support to meet their needs (Koder & Helmes, 2006).

Research has shown that older adults who engage informal aged care, experience the greatest health impacts due to normative aged related health concerns exacerbated by stressful carer responsibilities (O'Connell, Bailey, & Walker, 2003). As their care recipients are often in their own age group and increasingly dependent on them, the carer is often left with little time and energy to attend to their own social and health care needs. There are also reports that older adults involved in substantial caregiving are at a 50% greater risk of experiencing clinically significant anxiety and depression (Butterworth et al., 2010). In fact, caregiving fits the formula for chronic stress so well that it is used as an exemplar in researching the health impact of chronic stress (Vitaliano, Zhang, & Scanlan, 2003).

Although deleterious caregiving consequences are still the main concern in most carer literature, the positive caregiving literature demonstrates that caring for older persons can also be a perceptually positive experience (Hanyok, Mullaney, Finucane, & Carrese, 2009). Beneficial aspects of caregiving include feeling useful, adding meaning to one's sense of self, as well as a sense of mastery and satisfaction (Shirai, Silverberg Koerner, & Baete Kenyon, 2009). However, providing care and support to another is a dynamic process. As the needs and condition of the care recipient alter, so begins continual change and adjustment within the caring relationship, as well as the role of the carer. Therefore, the role of an informal carer can accrue difficult personal issues surrounding matters of duty, adequacy and guilt (Oyebode, 2003). It is these types of psychological impacts that inspired the present study.

Throughout this paper, the term informal care is used to broadly define the unpaid support provided to an older person. This may be the only source of help that the individual receives, or it may be provided along with formal assistance. It includes a variety or

unregulated activity, such as practical supportive tasks and emotional support. The term carer burden is used to describe the stress, tension, and anxiety that carers experience (Lai, 2009).

The purpose of the present study was to enhance our knowledge of the psychological impact on older women who are informal carers, and explore the meanings that women ascribe to their experiences. Thus, as much of the research demonstrates that the positive and negative impacts of informal aged care are directly linked to carer, caregiving, social and cultural factors, these are discussed first. The affective aspects of providing informal aged care are then outlined in relation to their importance to caregiving. These include the concepts of anticipatory grief, interpersonal suffering, role captivity, isolation, guilt, and higher level gains.

Factors Influencing Carer Outcomes

Several factors affect how stressful, tolerable or satisfying informal carers perceive their role to be. Some of these correspond to the caregiving situation, others relate to socio-cultural factors, as well as the individual characteristics of the carer and the care recipient. It is not possible to change symptoms and diseases of the care recipient, thus, care recipient factors will not be examined. It is more important to focus on areas where change is possible, such as carer's functional coping strategies. As discussed next, developing a greater understanding of these factors could help mitigate the incidence and prevalence of negative caregiving outcomes.

Carer factors. Socio-demographic factors, relationship with the elder care recipient, as well as gender, can all influence carer's perceptions of their role (Vellone et al., 2011). For instance, female carers are known to experience more depressive symptoms, stress, and lower levels of mastery compared to their male counterparts (Marco et al., 2010; Mehta, 2005). A quantitative study comparing carers of demented elderly people with non-carers discovered that women carers were more burdened than both caregiving men and non-carers. Via a self-

report method, the women demonstrated poorer levels of health, greater restrictions to their social life, as well as a higher degree of conflict with other family members (Almberg, Jansson, Grafstrom, & Winblad, 1998).

One psychological explanation for the challenges faced by informal carers mentioned above is that men may be less likely to attend to their emotions, therefore less likely than women to express them (Lutzky & Knight, 1994). Also, perhaps as a result of traditional gender roles, many women have spent their adult years caring for children and others, thus they may feel distressed over finding themselves in another caring position (Oyebode, 2003). Nonetheless, carers who experience high levels of distress have a greater tendency to use emotion-focused coping strategies, such as denial, avoidance, and self-blame. These types of strategies are often associated with more negative health outcomes, such as depression and anxiety (Kramer, 1997; Minna et al., 2012).

The carer's relationship with the older care recipient is also a factor that can either improve or diminish the impact of caregiving. For instance, research has shown that spousal carers as well as adult children, perceive more caregiving benefits compared to other types of carers (Bien, Wojszel, & Sikorska-Simmons, 2007; Koerner, Kenyon, & Shirai, 2009). To the contrary, it has also been conceded that spouses and adult children of elderly people are the most vulnerable to the negative outcomes of caregiving (Sewitch, McCusker, Dendukuri, & Yaffe, 2004). In part, this disparity reflects the multidimensional nature of carer burden, which includes physical, emotional, financial, and social dimensions.

Caregiving factors. Caregiving factors per se, such as time of care and time lapsed from the beginning of the caregiving role, can also impact the caregiving experience (Vellone et al., 2011). While some quantitative studies argue that the negative impact of caregiving remains stable and unaltered over time (Levesque, Ducharme, Zarit, Lachance, & Giroux, 2008; Martinez-Martin et al., 2008), others propose that the more time lapsed from the

beginning of the caregiving role, the less the negative impact (Nir, Greenberger, & Bachner, 2009).

Adaptation theory has attempted to account for the latter claim. The theory highlights that people adapt to stressors when exposed to them over time, thus reducing their sensitivity through familiarity (Miller & McFall, 1991). Although familiarity can emphasise carers' helplessness and inability to control aspects of the caregiving process, having the ability to accept stressor consequences can also provide carers with a sense of control over caregiving outcomes. To the contrary, stress proliferation theory recognises that as daily stressors accrue, individuals become increasingly overwhelmed by their continuous and cumulative effect (Pavalko & Woodbury, 2000). When these stressors impinge on emotional coping strategies, carers can become extremely vulnerable to additional stressors. Consequently, this can place carers at risk for severe emotional repercussions, such as fatigue and depression (Uren & Grahamm, 2013).

Socio-cultural factors. A few studies have attempted to explore the reasons why some individuals continue to provide care to older adults in lieu of the difficulties accrued (Hsu & Shyu, 2003). Among the cited reasons were the social and cultural values of familism, filial piety, as well as gendered norms. Familism defines the normative feelings of attachment, loyalty, and reciprocity that family members have toward their familial relationships (Sayegh & Knight, 2011). The noblest aspects of familism, including altruism and interdependence, can lead to positive carer effects, such as fulfilling personal desires in the service of others (Flores, Hinton, Barker, Franz, & Velasquez, 2009). However, familism can also result in poorer mental health outcomes for carers. For example, using a path model, an association was detected between familism and avoidant coping in a sample of White and African-American carers of people with dementia (Sayegh & Knight, 2011). Familism has also been linked to dysfunctional thoughts and depressive symptomatology among 334 Spanish carers

(Losada et al., 2010). These studies argued that familism was not protective against carer's health, or representative of positive feelings surrounding family support. Instead, it was indicative of a sense of obligation and duty.

Similarly, filial piety has been shown to adjust adult children's attitudes and behaviours towards their ageing parents to ensure the continuance of parental wellbeing (Lai, 2009). This practice expects children to sacrifice their own social, financial, and physical interests out of responsibility to their parents (Dai & Dimond, 1998). Thus, filial piety can lead to a transcending of carers self-interest, as well as unwillingness to access formal support as a means of avoiding social stigma for being unfilial (Chee & Levkoff, 2001). Filial piety can also serve as a protective measure in caregiving. Lai (2009) argues that actions such as fulfilling responsibility and harmonising the family can indirectly reduce carer burden by altering carer appraisals of their roles. It is unclear, however, whether and how filial piety in the context of caregiving operates in ethno-cultural groups of Australian descent. To date, little research connects obligatory beliefs with the wellbeing outcomes in Australian carers.

According to feminist scholars, caregiving responsibilities are assumed by women due to cultural norms of women as natural nurturers, and cultural expectations that women should prioritise their family needs over their individual desires (Harrington-Meyer, 1999; Tronto, 1993). Subsequently, the issue for women is not whether they *should* care for another, rather it is *how* they should care for another and how they should deal with caregiving consequences (Tronto, 1993). However, caution should be taken against universalistic assumptions concerning the value of care among women, as few studies have explored how women from various cultural backgrounds experience and negotiate caregiving challenges.

Affective Aspects of Informal Caregiving

Given that caregiving can be detrimental to one's health, it is appropriate to examine what affective aspects of the caregiving experience account for these effects. It is also important to note that caregiving involves an interpretation of the caregiving situation, which cannot always be observed. Therefore, similar caregiving actions can have different meanings for different carers.

Anticipatory grief. In carers, anticipatory grief is a complex response to losses that occur prior to the care recipients' death. It is particularly common in those who care for dementia patients as the median life span after diagnosis is approximately 5-8 years (Xie, Brayne, & Matthews, 2008). A systematic review discovered that dementia carers experience anticipatory grief as a series of losses for themselves (e.g., companionship, freedom, and control), and for the care recipient (Chan, Livingston, Jones, & Sampson, 2013). Other studies have found that anticipatory grief in carers of people with dementia, causes an increase in depression levels (Kiely, Prigerson, & Mitchell, 2008; Sanders & Adams, 2005). Using depression scales, grief accounted for 32% (Kiely et al., 2008) and 48% (Sanders & Adams, 2005) of the common variance. This is significant as it suggests that what appears to be clinical depression in carers, may in fact be a grief reaction.

For some carers, anticipatory grief losses are felt much greater than post-death grieving (Rando, 2000). This may be because anticipatory grief has far more elusive consequences due to the lack of finality and the incompleteness of the loss. For instance, a qualitative study observed that carers felt that it was as if their dementing relative was already dead and that their passing would be a blessing. Similarly, Meuser and Marwit's (2001) study, which addressed the grief responses of spouse and adult children dementia carers ($N = 87$), found that within the grieving process, adult children expressed a similar desire for their parents to die. Reasoned responses for this included that carers did not want their care

recipient to suffer a slow and agonising death (Meuser & Marwit, 2001). These emotions can restrict carers from processing grief responses in an open and adaptive manner. Thus, carers may experience anticipatory grief losses more intensely as a result of their failure to complete normal grieving tasks (Chan et al., 2013).

From these studies, a picture of grief in dementia carers has begun to emerge. To date, however, no studies have examined the differential impact of grief and loss on a variety of carer types. Doing this would enable researchers to identify modifiable risk factors that would assist a diverse range of grieving carers to cope. Because each carer experiences grief and loss in an unparalleled way, such examination conducted phenomenologically would facilitate depth of understanding of subjective carers' experiences.

Interpersonal suffering. The experience of care recipient suffering has received considerable attention, however, research on the direct influence that this has on carers' emotional experiences and psychological wellbeing, is scarce (Monin & Schulz, 2009). Studies have shown that exposure to another's distress can lead individuals to experience similar emotions (e.g., despair in response to despair), and/or complementary emotions (e.g., love in response to despair) (Hatfield, Rapson, & Le, 2008; Keltner & Kring, 1998). People may also react to another's vulnerability defensively (e.g., anger in response to despair) (Rholes, Simpson, & Orina, 1999). Whilst complementary emotions motivate important social behaviours such as helping, nurturing, and forgiving, defensive emotional responses are usually orientated towards protecting oneself against feelings of insecurity (Monin & Schulz, 2009).

The latter claim has been reinforced by caregiving research on expressed emotion. High expressed emotion focuses on family members hostile and cynical attitudes towards their care recipients' suffering (Croog, Burleson, Sudilovsky, & Baume, 2006). Carers may do this by finding fault in the person they care for. For instance, carers may say "he knows he

shouldn't be doing that. He is so stubborn and it's his own fault that he's in pain" (Monin & Schulz, 2009). To the contrary, carers may try and protect themselves from other's suffering by making overly positive self-evaluations, amplifying perceptions of mastery and control, as well as being excessively optimistic (Taylor & Brown, 1988). Although chronic exposure to another's suffering can take its toll on caregiver wellbeing, the expression of caregiver suffering can also be adaptive. It not only communicates a need for support, it also prompts others to attend and respond to that person's needs (Monin & Schulz, 2009).

Perceptions of suffering could be most predictive of carers' emotional reactions, however, most research on interpersonal suffering is limited by the use of multidimensional measures (e.g., quality of life scales). These only measure a portion of psychological suffering, failing to take into account a variety of components, such as existential/spiritual suffering (Monin & Schulz, 2009). Because the experience of suffering is subjective, carers could be asked simple direct questions, such as "Are you suffering?" This would help capture a broader range of psychological phenomena.

Role captivity. Role captivity in caregiving has been measured by the concepts of "free to live one's life", "wanting to run away", and "entrapment by care recipient's illness" (Pearlin, Mullan, Semple, & Skaff, 1990). Entrapment defines an individual's strong desire to escape an experience, yet feeling blocked or unable to. Congruently, if carers feel trapped by the demands of their role and are unable to escape, they may experience a perceived lack of control (Martin, Gilbert, McEwan, & Irons, 2006). These findings are consistent with research on learned helplessness in female dementia carers, in which the combination of perceived loss of control and a propensity for self-blame, correlated with depression (Dixon, 1998; Mace & Rabins, 1981; Pagel, Becker, & Coppel, 1985).

A quantitative study also observed an association between entrapment and depression in individuals from a dementia carers' support group (Martin et al., 2006). However, these

findings must be interpreted with care as many of the carers reported that they had also experienced a perceived lack of social support. The availability of social support is important for coping with carer strain as it provides emotional sustenance and creates a buffer against burden (Savage & Bailey, 2004). Therefore, it is possible that the findings may also be attributed to the limited amount of social support received.

     Isolation. In their retirement years, many adults make plans to travel or to pursue leisure interests and activities. The onset of illness in a care recipient shatters these dreams and carers can be left with no hope or plans for their own future (Phillips & Rempusheski, 1986). The interruption to plans and lifestyle becomes both frustrating and demoralising, whilst a lack of hope acts as an isolator (Tebb, 1994). This can lead to reshaped self-concepts and engulfment in the caregiving role. Both engulfment in the caregiving role and a greater loss of self are associated with a lack of social roles and limited social contact. When older adults lose their opportunity for social interaction, isolation and depression can ensue (Francell, Conn, & Gray, 1989).

     Feelings of carer isolation are not only related to the amount of contact that carers have with others, they can also be associated with inadequate amounts of social support, a perceived lack of community resources, self-neglect, as well as poor quality relationships (Baumgarten et al., 1992; Pearson, Verma, & Nellett, 1988; Tebb, 1994). For instance, when couples lose the companionship that they once had, they can experience relational deprivation and a sense of loss (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000). Without someone in whom they can confide, carers can be left feeling angry, depressed, and isolated (Cohen & Eisdorfer, 1988). However, most studies, which have focused on isolation in carers have failed to take into account how positive effects of caregiving can impact negative effects (e.g., isolation). This is an important factor, as research has identified that positive and

negative effects of caregiving often coexist, and that positive effects have the potential to counterbalance negative ones (Bassi et al., 2014).

Guilt. Although clinical literature has long acknowledged the concept of guilt as a prevailing emotion experienced by family carers, it is only now surfacing as a key construct in carer burden (Gonyea, Paris, & de Saxe Zerden, 2008). For instance, a cross-sectional postal survey given to 221 British dementia carers examined the relationship between guilt and caregiving (Roach, Laidlaw, Gillanders, & Quinn, 2013). Carers endorsed high levels of guilt across most of the following factors: "doing wrong by the care recipient", "not meeting caregiving challenges", "self-care", "neglecting other relatives", and "experiencing negative emotions towards caregiving". Similarly, Gonyea et al. (2008) also sought to explore strains of guilt on adult daughters who cared for their ageing mothers. Guilt was identified as a widely experienced emotion, with 65% of adult daughters expressing some degree of performance guilt (Gonyea et al., 2008).

Based on a twelve item "caring shame and guilt scale", Martin et al. (2006) found that shame, but not guilt, was significantly associated with depression in carers. This is surprising considering that guilt is congruent with depression in the general population (Kim, Thibodeau, & Jorgensen, 2011). One possible explanation for this is that the findings were confounded by the use of a scale that failed to indicate a cut-off point for dysfunctional guilt. Guilt is a uniquely individual experience, thus, results may have been different had participants given verbalised accounts of how their guilt was experienced. This would have enabled richer descriptions of how participants experienced guilt, and in what situations this emotion was activated.

Higher-level gains. Although a relatively unexplored topic, recent research has identified religion and spirituality as important coping resources for carers (Herbert, Weinstein, Martire, & Schulz, 2006; Sanders, 2005). Religion commonly refers to a doctrinal

framework that guides one's beliefs under a broader faith community. Spirituality, which may or may not be linked to a specific religion, is more focused on a search for meaning in life, or a connection to a transcendent purpose (Stuckey & Gwyther, 2003).

A national poll survey in the United States found that practices related to religion and spirituality were among the most important coping mechanisms for carers. Seventy three per cent of respondents reported that prayer had helped them cope with the demands of caregiving (National Alliance for Caregiving and the AARP, 2004). Findings in the previous study were consistent with the findings of Stuckey (2001). Qualitative data derived from carers of people with Alzheimer's disease (N=20), who were of Catholic and Protestant faith, identified that religious and spiritual beliefs and practices had helped carers to make sense out of a stressful situation (Stuckey, 2001). Sanders (2005) also discovered carer gains of spiritual growth, personal growth, and a sense of mastery, in carers of people with Alzheimer's disease. Carers who indicated spiritual growth gains were of Christian faith. Religion and spirituality are considered important dimensions to the human experience, thus these findings should be confirmed with other populations of carers, and also in those who are not committed to a particular religion.

Limitations of Existing Literature and the Rationale for the Current Study

There are a number of reasons for the complex findings in the literature regarding the psychological impact of informal aged care. First, many of these studies were from various regions around the globe; Britain, Spain, and the United States. All of these have cultural variations that may influence how informal carers perceive their caregiving experience. Moreover, a diverse range of assessment measures were used, such as self-reports, depression scales, and cross-sectional surveys. Hence, the majority of studies discussed thus far utilised a quantitative approach. Whilst this allowed gathering data from large numbers of participants, it did not investigate carers' subjective experiences in-depth. Qualitative studies allow

researchers to examine, as far possible, rich interpretative accounts of participants' experiences, which are not so easily "measured".

In most informal carer literature, age has either not been addressed due to design constraints or it may have simply not been discussed. The few studies that did concentrate on older carers were focused on a particular care group like dementia, rather than the characteristics of specific carers. Despite the importance of these contributions, little research has disclosed the subjective perceptions and emerging needs of older caregiving women. Furthermore, the issue of how informal caregiving shapes their lives has seldom been addressed.

Given that the rate of older Australians is set to increase significantly, more individuals will find themselves challenged by informal caregiving. Studies exploring carer's experiences of informal aged care are lacking in Australia. Considering the prevalence of informal caregiving in this age group, as well the psychological implications incurred, the lack of research in this area is concerning. Hence, research, which attempts to support these carers in their roles, and which essentially aims to reduce the negative impacts that caring can impose on their health, should be prioritised. Therefore, the present study engaged an in-depth qualitative exploration of the lived experience of older female informal aged carers. By shedding light on the psychological impact of informal aged care, the findings help to identify potential supports for carers, as well as further the knowledge base for informing contemporary health and social policies. Based on these premises, the research question posed by the present study was: What are the perceived psychological impacts of aged care on older women who are informal carers?

Research Design

Methodology

The present study employed a qualitative research design aiming to gain an in-depth understanding into participants' subjective personal experiences of the phenomenon of being informal aged carers. An interpretative phenomenological methodology was utilised to access participants' inner worlds and to explore how they ascribed meaning to interactions and lived experiences within their environment. Interpretative phenomenological analysis (IPA) is based on a social constructionist epistemology (Smith, Flowers, & Larkin, 2009). This was relevant to the present research question as it embedded knowledge and truth in social interchange and emphasised the influence that social context had on the meaning attributed to participants' experience (Gergen, 1985). Thus, the subjective lived experience of older female informal aged carers was explored against the socially constructed background of informal aged care.

IPA's theoretical underpinnings stem from phenomenology, symbolic interactionism, and hermeneutics (Smith, Flowers, & Larkin, 2009). IPA is phenomenological in that it intends to interpret and understand participants' subjective claims and concerns rather than the formulation of their objective accounts. IPA is also informed by symbolic interactionism, with its concern for how meaning is derived by individuals within both a social and personal world (Smith & Osborne, 2008). Further, IPA is based on hermeneutic principles whereby interpretation is central to understanding. Heidegger's hermeneutic phenomenology contributed to the theoretical framework by recognising the researcher's centrality to the research and analysis (Brocki & Wearden, 2006). This allowed participants' lived experiences to be revealed on their own terms, without the imposition of any preconceived assumptions from the researcher (Larkin, Watts, & Clifton, 2006).

It has been argued by Thorne (1997) that a sense of meaning is the foundation that contextualizes all other levels of health. Thus, guided by the principles of IPA, the present study aimed to explore participants' subjective accounts of informal aged care. The goal was to understand how participants made sense of their caregiving experiences and the meaning that they attributed to them.

Participants

Ten female informal aged carers were interviewed. A criterion sampling method was used whereby participants, who had the desired experience, agreed to participate. Participants' ages ranged from 65 to 76 years, with a median of 71 years. All participants provided informal care to a care recipient who was also over 65 years. All were lucid and cognitively able, and all resided in the Perth metropolitan area. A table relating to participant demographics is found in Appendix A.

In keeping with this methodological framework and based on the researchers' determination that an idiographic mode of inquiry was developed (Smith & Osborn, 2003), recruiting participants ceased at 10 interviews. An idiographic perspective allows the researcher to find levels of analysis which recognise patterns across cases while still acknowledging the uniqueness within each individual's life (Smith, 1999). As an exception, the researcher also chose to include data from one participant whose spouse had died three years ago. The decision to include the data was made on the basis that the data enriched the research, rather than corrupted it. This participant's experiential depictions combined with her caregiving journal notes demonstrated the enduring nature of the psychological impact.

Materials

Participants were given an informed consent letter (Appendix B), as well as a detailed information letter (Appendix C) containing counselling referral details (e.g., Crisis Care). A semi-structured interview schedule (Appendix D) consisting of exploratory questions and

prompts was used as a guide. A digital audio recorder was used to capture interview dialogue and note-taking equipment was at hand to take notes when necessary. Additionally, a reflective journal and audit trail were kept by the researcher. All data were stored on a laptop.

Procedures

After obtaining ethical clearance from the School of Psychology and Social Science Ethics Sub-Committee, the research supervisor facilitated contact with Carers WA. This is a not for profit community based organisation that represents Australia's carers (Carers WA, 2014). After gaining ethics approval from Carers WA and securing their participation, carers were invited to participate in the proposed study via social networking services. This comprised an advertisement on Carers WA's facebook page as well as in their e-bulletin newsletter. Participants were also recruited via social referral (e.g., word of mouth). Those who showed a willingness to participate were provided the researcher's contact details and asked to make contact to discuss their participation further.

Interview date, time, duration and purpose were discussed with participants over the telephone, with participants and researcher agreeing on a safe and quiet location. On nine occasions the interviews were conducted in the participants' own homes, whilst another was conducted in a church. Details were reiterated in an information letter mailed to participants prior to the interview, inviting them to participate. The information letter also contained counselling details. These were to be used by participants in the event that interview issues became emotionally upsetting. A letter of informed consent was issued prior to interview commencement and signed in the researcher's presence. This contained information relating to the research purpose, confidentiality, freedom to withdraw, contact details, and consent to audio record the interview. Participant interviews were conducted over a four week period.

The use of a semi-structured interview was used to guide the interview schedule rather than dictate it. This approach to interviewing best meets the needs of a qualitative

study as it represents both consistency and flexibility (Langdridge, 2007). Consistency was maintained through the use of an interview schedule, whilst flexibility was displayed by the researcher working with the questions in light of the conversation that occurred with the interviewee. This enabled a joint exploration of the participants' world view in relation to the topic. It also coincided with the nature of IPA. That is, IPA views existence as non-static, often paradoxical, and ever changing (Conroy, 2003).

In keeping with the focus on the lived experience of the phenomenon, the researcher commenced each interview with the following phenomenological question: "Can you please tell me about informal aged care in your life?" Depending on the response, the researcher asked another question from the interview schedule or interjected with an appropriate follow-up question if the response diverged from the topic. For example, in one instance the participant disclosed her frustration at feeling burdened with the caregiving responsibility, so the follow-up question was "Can you please tell me about any formal support that you are getting as an informal aged carer?" At the conclusion of each interview, participants were asked if they had anything else that they wanted to add.

Interview questions were established based on an extensive review of informal carer literature. Topics included coping strategies as well as challenges. Interview questions were grouped thematically and memorised, thus eliminating the need to refer to the schedule during interviews. These were framed in an exploratory and clarifying way to encourage expansive answers.

Throughout the interview process, the researcher adhered to Egan's (1998) SOLER principles. These contained essential micro-skills that facilitated effective communication and support (i.e., sit squarely, open posture, lean forward, eye contact, relax). Each interview lasted between 60 and 90 minutes and was recorded via a digital audio recorder for later verbatim transcription. This ensured participant responses were captured in their own words

and that the focus was on the topic and interview dynamics. Contemporaneous and discrete field notes were taken throughout the research process and arrived through active listening, procedural details, observations, and reflections.

Data Analysis

Data analysis was conducted in accordance with Taylor and Bogdan's (1998) thematic analysis steps and guided by IPA principles. Via an iterative and inductive cycle, the interpretative analytic process aimed to reflect an interpretative account of the women's depictions of their experiences. This process enabled analytic attention to be directed to the participants' attempts at making sense of their experiences through reflective engagement with their personal accounts (Smith et al., 2009). Further, data analysis aimed to identify categories, themes, relationships, and assumptions that comprised carers' views of their world, and in particular, their role. An objective of the study was to capture both particulars of each caregiving experience, as well as the general properties of psychological impact as they emerged from the data.

Aligned with the evolving and flexible nature of phenomenological inquiry, the transcription process commenced prior to completion of all interviews. This allowed information to be retrieved that could guide subsequent interviews. The analytic process proceeded from reading and re-reading transcripts together with audio recordings, allowing for data familiarisation. Personal biases and questions were then identified and recorded, whilst attention was paid to participants' meaningful words, statements, concepts and metaphors. Conceptualisations of data were reflected upon in the researcher's journal. This greatly aided the process by helping to make connections across emerging themes.

Following this, section content was summarised, comprising of the total responses to questions. Data reduction then elicited a list of codes and significant statements were allocated to relevant codes (e.g., carer-emotional affect-negative). Finally, the data set was

further reduced, themes were renamed, and common codes were grouped to over-arching themes. To counteract discrepancies, thematic analysis steps were repeated until participants' experiences were meaningfully interpreted.

Research Rigour

Reflexivity

As a current student of psychology, the researcher acknowledges the future career interests that she brings to the present study. Also, in recognising who she is as a researcher on this subject, she is able to accept that advocating for the chosen participants is a potential bias. She further acknowledges that she has at some point been an informal carer. This resulted in her questioning: "Are there any differences in the experience of caregiving, and if so, how do these differences impact the carer?" The researcher was aware that her caregiving experiences were mostly rewarding, however, that this may not be the case for all carers. Awareness of these biases encouraged a critical examination of the influence that she had over participants and it prompted a revised way of being and relating. It also placed an imperative on the researcher to step outside the frame of caregiving and to view it in a new light.

Committed to transparency and reflexivity, the current researcher kept a reflective journal. It included experiential depictions, beliefs, and things to do. Writing and reflecting aided a continuous and genuine examination of the researcher's own values, presence, preconceptions, and those of the participants, which may have affected the interpretation of responses. Journaling proved generative in clarifying the research purpose and why it was worth pursuing (to identify potential support for informal carers). It also promoted paradigmatic consistency and methodological rigour (i.e., as a guide to triangulate interpretations against) (Laverty, 2003). Without this method of self-examination, the researcher would have risked credibility and interpretative rigour.

Triangulation

In qualitative research, truth depicts accurately an independent existing reality (Guba, 1990). In the current study, the criteria for judging the trustworthiness of interpretations and findings comprised triangulation. This involved the processes of member checking, supervisor debriefing, and the use of an audit trail. Member checking was facilitated via communications verifying interpretations with three participants. All three participants reported back that the themes accurately represented their experience. This validation process increased the credibility of the research findings, certifying the women's experiences.

Regular debriefings with the research supervisor enabled consideration of other perspectives and interpretations of the data. Dependability and confirmability of the data were established with the use of an audit trail. This comprised comprehensive notes related to the contextual background of the data and the rationale for all methodological choices. Transferability, involving suitable judgement about how well the findings of the study could be transferred beyond the study's sample, was enhanced with the use of detailed descriptions of contextual accounts, research methods, and examples of raw data.

Ethical Considerations

Conducting research with older people can involve ethical concerns surrounding issues of power and confidentiality. Thus, the researcher briefed participants so that they were aware of the power they had over their level of responses, and people and place names were replaced by pseudonyms throughout transcription and analysis. Data were also de-identified with transcripts stored separately from participant details.

Findings and Interpretations

Themes relating to the psychological impact of informal aged care were identified, which reflect and extend upon the domains identified in existing literature. Analysis captured three major themes: personal; spiritual; and socio-cultural. Within these themes, seven

subthemes emerged, as illustrated in Table 1. Whilst carers are typically silent about their pains, as they believe complaining to be a form of betrayal both personally and socially, participants said that having an opportunity to share their caring experiences were beneficial. All now believed that their stories bear telling so that vulnerable others may be empowered to do the same. All appreciated being given the opportunity to have a "voice". The findings relating to the themes are presented herein, including relevant participant quotations to support findings and interpretations.

Table 1

Themes and Subthemes Relating to the Psychological Impact of Informal Aged Care

Themes	Subthemes
Personal	Feelings of Uncertainty
	Feelings of Guilt
	Feelings of Entrapment
	Feelings of Loss
Spiritual	A Sense of Meaning
Socio-Cultural	Socially Isolated
	Socially and Culturally Obligated

Personal

The personal impact incurred from the women's caregiving experience was a recurrent theme throughout the interviews. This theme reflects the cumulative effect on the women's emotional wellbeing. Four key subthemes were identified within this theme: uncertainty, guilt, entrapment, and loss.

Feelings of uncertainty. Most of the carers in this study expressed uncertainty. The apparent pressures of uncertainty were shown in terms of making care decisions, uncertainty

over carers' own declining health, as well as fear and doubt over the future. In thinking about

her own ailing physical and mental health, one woman expressed concern over who would

continue to take care of her sister:

> *So who would take that role on then? Well, her grandchildren wouldn't do it because they are boys to start with. But then what about her daughter taking on some responsibility? Well, she is also struggling to exist herself. Me and my sister are the only ones who can help one another.*

Mrs A described how she avoids thinking about the future. Her inability to embrace it evoked

anxiety and fear. This style of avoidant coping is consistent with what Minna et al. (2012)

described as emotion-focused coping strategies. Like most of the carers, Mrs A avoided

confronting aspects of her future because it caused high emotional distress. By tapping an

avoidant style of emotional regulation, most aimed to relieve adverse emotional impact.

Thinking about the future did not come easily for Mrs J either: "*Knowing that they're*

not going to get better is very difficult. There is nothing that you can talk about that's in the

future. It's very difficult to talk about the present. You rely on the past". Her aversion to being

prospective had a self-protective quality to it. Mrs E also found it difficult to think about the

future because she was grappling with the harsh reality of her own declining health:

> *You don't really look to the future. In the back of my mind I'm sort of going well maybe I'll get this trip in next year. Maybe, maybe not. Before I get too old to do it. You just don't know what's ahead of you.*

Mrs E described how this fear manifested in the form of seeing her life slip away before she

had an opportunity to enjoy it. In a similar way, Mrs D stated "*If I wasn't looking after him, I*

could have been travelling around somewhere. If I wasn't looking after him, maybe I would

have found somebody. I could have got married a second time". She continued to recall how

she had sacrificed her own independence to ensure that she was available for him. Although

Mrs D was acutely aware of her loss of independence, she chose to succumb to it as she felt

that there was no other option. A few carers chose to look past their fear about what the

future held. Instead of allowing fear to engulf them, they embraced it and chose to venture

into the unknown. These same women refused to allow uncertainty limit their own

independence. Instead, they responded by limiting their care recipients' independence. Mrs H

reflected on the measures that she took to ensure her spouse's safety:

> *So anyway, we do this walking group. Eight o'clock it starts. And now I don't allow*
> *him out of bed. I now say to him I don't want you out of bed until I come back. So he*
> *doesn't get up.*

This type of response to uncertainty has been referred to by Croog et al. (2006) in

their research on expressed emotion. Carers who experience high expressed emotion are

typically critical and hostile towards their care recipient. The uncertainty that Mrs H

experienced over her spouse's safety had led her to react with direct hostility and resentment

towards him. Resentment was obvious as she disclosed the manifold costs of his illness, in

terms of her wellbeing:

> *How I look at it is that he has no choice. He's got the illness for all of his life.*
> *Whether I'm here or not, he's life would be the same. But as a carer, and a*
> *reasonably healthy one, my life would be different because I've got choices.*

Mrs H also spoke of feeling overwhelmed by being a surrogate decision maker. In fact,

several women experienced feelings of doubt around care decisions. Doubt was most

prominent when ambiguous illness symptoms prevented the carers from confidently

appraising their care recipients' wellbeing. Mrs F experienced doubts surrounding her ability

to understand how her parents were affected by cognitive disabilities:

> *It's trying to figure out how to deal with them. It's sad to see them declining. You sort*
> *of don't know how far to let them go because you get into the danger zone. So, it's*
> *been a really bad learning curve for us.*

When uncertainty led to stress and despair, most of the carers attempted to reduce the

uncertainty with avoidance strategies. According to Brashers (2007), uncertainty results in an

emotional response that influences a behavioural action aimed at reducing, maintaining,

increasing, or adapting to the uncertainty. Most of the carers aimed to maintain the

uncertainty by selectively avoiding information that they perceived to be threatening. The theme of uncertainty is salient as it also touches on the themes that follow.

Feelings of guilt. The carers frequently described feelings of guilt. Three forms of guilt were apparent: guilt about making care decisions that may make the care recipient unhappy, guilt over breaching a moral standard, and guilt over experiencing negative emotions towards caregiving. One of the carers highlighted her guilt over making decisions for her husband:

> *If I could get respite care....I know that he'd have to go into a hospital or something like that. But he wouldn't want to do that. And so the drama of having to do that would take the pleasure away. I'd feel guilt, yes, definitely. He would make me feel very guilty.*

Mrs E's realisation that her husband would not be happy about being placed in respite care was compounded by the guilt that she felt over limiting his independence. When preparing to take steps that would decrease the care recipient's sense of autonomy, many carers expressed guilt. This was particularly notable when longstanding parent-child roles became reversed and adult children were forced to make important decisions for their parents. Mrs F described how her parent's insistence on living in their own home and independently, left her feeling guilty when searching for nursing home placements:

> *It was a disaster because every time dad goes to hospital, you know, we've got to fly down here or he flies up there. It's just one of those things where you think is it because of us or is it because of them? It's certainly a ride and a half.*

Mrs F was aware that taking away her parents' independence would leave them unhappy, which would make her feel guilty. Mrs D was also concerned about making decisions that would not harmonise with her father's:

> *Like my aunty is meant to go to an old people's home and my dad goes "Boy, she's got a daughter and a son, so why can't they look after her?" He's against that completely. He would not go. You know he's like "I've got you here and you have to look after me".*

Consistent with Gonyea et al's. (2008) findings, many carers perceived caregiving as a moral responsibility due to internalised norms regarding nurturing responsibilities. They defined their identity in the context of their caregiving relationship and then judged themselves based on a moral standard of care. This sentiment was echoed by Mrs H, who expressed that she would be violating a moral standard by using formal support services:

> *You know everybody says to me that I should get a cleaner and I should get this. But why should I? Why should I use the government's money when I can do it? We get nothing from the government because I just feel that there are other people out there that deserve it more than us.*

Similarly, Mrs D articulated that despite the heavy caregiving burden, she would never ask for support because she would feel guilty over breaching her filial responsibilities: "*I'm not ready to ask for help yet. It's very hard to look after an old person, but you have to because it's your father. If it was somebody else then it's a different story. It's a big burden*".

All of the carers reluctantly acknowledged that they wished to be released from the excessive burden of care. Four expressed, somewhat abstractly, a desire for their care recipient to die. However, the current study yielded an unexpected result that does not support other research suggestions. Unlike Meuser and Marwit's (2001) findings, in which carers expressed a wish for their ageing care recipient to die so that they would not suffer a slow and agonising death, these women were hoping to be relieved from their caregiving burden. As might be expected, their reactions were accompanied by intense guilt. Mrs G poignantly described: "*If carers were honest, at times when you're exhausted you think, oh, why don't you go to God? Why don't you die? And that's not a nice thought, but it's crossed my mind*".

Although she was simply overwhelmed and desirous of relief, Mrs G did not believe that her care recipient's death was the solution to her concerns. Along with many of the carers, she had growing expectations that a new manifestation of burden (in the form of grief) would supersede any relief. Most of the carers already displayed the core features of

anticipatory grief, including guilt, anger, and uncertainty about the future (Chan et al., 2013).

Guilt was most notable in the spousal carers when discussing a desire for personal freedom.

According to Mrs C:

> *You know I'd like to everyday, go for a walk or go to the river and go for a walk down the river, and things like that. I think I could be doing so many things, but it's no blame thing because, you know, I mean he just can't. It's not his fault.*

All of the carers demonstrated guilt over experiencing negative emotions. This type of

carer reaction originated through social expectations that serve to guide customary

behaviours of caring (Hunt & Smith, 2004). The norm of social responsibility motivates

people to help those in need, especially if those people are not to blame for their

circumstances (Weiner, 1980). In this study, the carers felt guilty for violating this norm and

for experiencing negativity towards a role that benefits those who are vulnerable.

Feelings of entrapment. A number of carers talked about feeling trapped by their

caregiving role. Notions that shaped the carers' mindset of entrapment included a lack of

freedom, limited support, expressions of limited choices, and feeling powerless. Several

carers had taken on a "siege" mentality in which escapist thoughts emerged:

> *It's shocking the thought of what I'm going to say now, but it's the truth. Sometimes I wish I could die because that's the only way out of it. And I'm a very strong Christian, but I say God, for God's sake, take me. Put me out of this misery.*

Mrs E also echoed sentiments of wanting to escape: *"It's just that I'm stuck here. I play*

patience, I play games, which you know, occupies my hands and mind. It's not terribly

fulfilling, but it's an escape". She continued on to explain that she saw no option to escape

her predicament of caregiving, so she must accept it. Some carers believed that acceptance of

their caregiving situation was appropriate, rather than resistance against inevitability.

> *Yeah, I do accept it. I accept it because I know that I don't have any other choice. I can't change it. I can't make it better. I can't leave. My goal now is to make sure that he has the best life that he can with what he's got. My purpose now is that as long as God is willing, I shall take care of him. I'm not saying that's what I really want, but that's the way it is because I can't change it.*

The inability to escape from the caregiving situation was a major hurdle in the carers' lives. Many reported how they expended considerable energy on focusing on just making it through the day. All described a palpable fatalism and passivity, consistent with the use of emotion-focussed coping mechanisms. They implied that they felt powerless not being able to do anything other than remain in their caring role. Unlike problem-focused approaches, emotion-focused approaches provide little sense of release or control. Instead, carers who engage this style of coping experience greater levels of emotional distress (Kramer, 1997; Minna et al., 2012).

All of the carers longed for time alone, and entrapment around a lack of freedom was exemplified with statements such as: "*I don't get the time that I need to do what I need to do*", and *"Oh, time is precious. I don't have enough for me"*. Mrs B demonstrated the restriction imposed on her life: *"Well, I've had to give up my care. Yes, it's sort of complicating my things. As I said, I need to try and have some balance in my life"*.

Like most carers, Mrs B was battling her own health concerns, and having to manage her mother's care on top of her own care was a tremendous struggle. Existing studies have found it difficult to differentiate between negative carer outcomes as a result of normative aging, and those due to caregiving (Lavela & Nazneen, 2010). These findings showed that carers experienced the most negative health outcomes from having to simultaneously fill the role of a carer and a patient, in a situation that requires a substantial amount of self-care. This adds further support to the notion that older carers experience the greatest health impacts due to normative age related concerns exacerbated by stressful caregiving responsibilities (O'Connell et al., 2003).

Not only did carers feel trapped by the inability to engage everyday facets of life, they were also constantly preoccupied with the care recipient in their thoughts. This was illustrated by Mrs F: "*It is exhausting because you think about it all night, and you think about the best*

way to cope with it. It's still there when you wake up. It's a constant demand". Mrs A also

described: "*I had a mental breakdown almost because I'm older, you know. Just the sheer*

mental exhaustion from the constant... you know. It's like looking after a baby again. It's like

a constant demand". Lack of cognitive coping resources caused overwhelming feelings of

entrapment that could not be dispelled.

Pervasive hopelessness emerged throughout the interviews, making it difficult to

conceal experiences of entrapment. Consistent with previous findings, the carers

demonstrated high motivation to escape, yet felt blocked or unable to (Brown, Harris, &

Hepworth, 1995). Some had even attempted to gain control over their situations by asking for

formal assistance. Several confessed that their efforts were fruitless:

> *You see I was having caring myself but I couldn't keep it up because I couldn't cope*
> *with what people can't do to help me. I'd say I really need somebody to do this. Oh*
> *no, we are not allowed to do this but we'll do this for you. I'd say look, while I can*
> *still do it, even with some difficulty, I would like to keep doing what I can do. I don't*
> *want people to help with what I can still manage. Help me with what I can't do.*

Another expressed:

> *And I think, at least she's got me shouting or screaming or jumping up and down to*
> *try to get help or something that is right for her. What about me? Who's going to*
> *shout or scream or do anything? If nothing changes, what am I going to have to put*
> *up with?*

In drawing on these carers' accounts, perceptions of formal support services were not

reminiscent of choice and empowerment. Rather, they were fraught with entrapment,

powerlessness, and frustration. Rationally, these carers knew that they could not attribute

their unwanted predicament to the care recipient whose illness was out of their control. Most

found an outlet for intense emotions by directing such at familial or formal service issues.

Retrospectively, this appeared to be a better option than engaging in a process of self-

recrimination.

The presence of entrapment was suggestive of carer behaviours signalling helplessness and hopelessness. These symptoms are indicative of depressive symptoms, thus supporting Pearlin et al's. (1990) view that role captivity (e.g., entrapment) is an important feature of depression in caregiving populations.

Feelings of loss. When reflecting on their current circumstances, carers demonstrated a strong yearning for their past and for normalcy, as well as aspects of grief. Loss of independence, relationships, and dreams were commonly expressed. Mrs H indicated her experience of loss as it pertained to past dreams that were shared with her husband:

> *I have to keep telling myself that I have nothing to be depressed about, but at the end of the day I do get down. I suppose it's the disappointment. I mean I worked until I was seventy so that we could have a good retirement. We were going to do all these wonderful things. We can't do them now. So I think it's, I think it's a sadness. I think why? It's a sense of loss.*

For many of the carers there was a dichotomy in relation to "how things were" and "how they are now". Mrs G stated:

> *The person I care for, we are never able to get out every day like we used to. You know, go out on the beach, have a coffee. That's all finished and so I'm just disappointed, but I accept it. But I miss it. And I miss that she used to be able to do those things. But she can't anymore because she is limited. So it limits me.*

Carers unknowingly described aspects of grief when talking about the care recipient who "was". This was to be expected as the prevalence of anticipatory grief in carers has been estimated at between 47% and 71% (Chan et al., 2013). Daughters grieved the final and absolute loss of the parent-child relationship, accompanied by expressions of helplessness. Helplessness was associated with knowing that things would never be the same again: "*It's hard to watch your parents going downhill. You know, they've always been there for me*".

For daughters, grief was focused on personal losses, such as a loss of freedom and sibling support. Mrs D explained how her personal freedom had been curtailed: "*I mean I could go for holidays, but where can I go now? What am I going to do with him? I can't*

leave him in the house by himself". Personal losses appeared difficult to accept. Powell

(1989) suggests that carers need to disconnect themselves from the caregiving role and accept

the significance of their personal losses. This may involve carers learning to cope with mostly

negative choices, wherein all alternatives are undesirable (Wilson, 1989).

In contrast to daughter carers, spousal carers were more focused on couple orientated

losses, such as lost companionship and shared activities. Mrs H stated:

> *And it's the little things, like we never used to go to sleep at night without holding*
> *each other or giving him a kiss. I can't do that anymore because his arms hurt. I can't*
> *even have a cuddle. It's those things. It's the little things.*

Although spouses expressed deep sorrow for that which can never be again, they were more

reality orientated than those caring for their parents. As the content of Mrs J's story revealed,

there was a strong sense of togetherness among spouses, as well as a quiet determination to

press on: "*I'd always say to him that we are in this together. This is a journey that we've been*

given, and therefore we are in it together. Because that's what marriage is all about".

Spouses demonstrated greater acceptance towards change, possibly as a function of

their spousal role and its position in the life cycle. In later life, spouses have a greater

understanding that ageing brings deterioration and death closer, and that eventually one must

prepare for self-sufficiency (Meuser & Marwit, 2001). Thus, a readiness for the inevitable is

what differentiated spousal carers from daughter carers in terms of a greater acceptance

towards carer losses and change.

Spiritual

When reflecting on their caregiving experience, most carers described how spirituality

had helped them cope with their caregiving role. Most salient was that spirituality had helped

them gain a greater sense of meaning in life. If there was any silver lining in the caregiving

experience, this was it.

A sense of meaning. The findings showed that it was mostly carers' negative experiences that provided motivation to search for meaning in their roles. Indeed, the issue of meaning of one's life is said to have no relevance until personal crises occurs (Deane, 1999; Frankl, 1973). Carers searched for meaning in their care recipients, others, and self. Throughout the interview, Mrs G searched for meaning in her caregiving experience through God:

> *So, I am finding that I'm tied down a little bit. But yeah, that's ok. I've got to zip up and say well that's what God wants me to do, to be the carer. Yes, if that's God's will for me to do, then I must accept that.*

Mrs G was a devoted Christian and she accepted the challenges and difficulties of caregiving out of a desire to do God's will. Nearly all carers revealed that they gained strength and a sense of purpose by trusting in their beliefs:

> *If you're tired and you haven't taken the right attitude in the fact that it's ok, you know God will, and he does. He gives me the time to get out and do my thing. And I must never stop thinking that this is what was planned.*

While only a few carers revealed their religious and spiritual affiliations, all demonstrated how spiritual aspects had helped transcend the daily vicissitudes of caregiving. Further, all showed that they had capacity to develop spiritual dimensions that could give meaning to their otherwise meaningless situations:

> *Some days I think what's in it for me? And there is nothing. So that's when I count my blessings because I've got so much to be thankful for. I say, well [husband] could be so much worse, you know.*

Another carer found meaning by affirming her ability to lead an ethical life of personal fulfilment, aspiring to the greater good of humanity: *"I think as long as you don't get bitter and twisted and fret, which sometimes you can, I think it gives you a reason to do it. Because you feel you are doing something for mankind"*.

It was clear that all carers experienced their roles as challenging and self-sacrificial, as well as rewarding. Although the concepts of sacrifice and reward may seem opposing, they

can espouse one another to produce greater meaning (Baxter & Braithwaite, 2010). Carers demonstrated how sacrifices led to more meaningful rewards, whilst caregiving rewards gave meaning to sacrifices. A reciprocal loving connection gave meaning to Mrs D's sacrifices:

> *I suppose some people might see it just as a job, but if you really care about someone emotionally it doesn't become a chore. It's a job but it doesn't become a drag or anything like that. It's like a labour of love.*

As a state of being, connectedness helped carers discover new meaning within their caregiving relationship. Often meaning was found by appreciating aspects of the care recipient that had previously been hidden:

> *I can actually relate to her and how I'm feeling now. Or she knows when I'm angry or miserable about something. She'll enquire and care and we can talk about it. It makes things feel a lot better for me.*

Carers expressed how bonding with their care recipient was a blessing displayed through mutual concern, loving affection, and gratitude. A new way of being and relating was created amidst the uncertainties of ageing. In moments of despair, carers dispelled notions of the "what if", in exchange for an appreciation of the present moment. Mrs F articulated: '*You navigate new moments as they come and you then you learn to go along with it"*.

Research has highlighted that when carers are exposed to their care recipients' distress they can experience complementary emotions, such as love and compassion. This can benefit the care recipient (Monin & Schulz, 2009). However, there is limited research regarding the effect on carers when the care recipient displays complementary emotions (e.g., compassion in response to carer despair). The current study suggests that complementary emotions aimed at the carer can reduce their burden. For instance, carers can meet their existential needs by finding some of their purpose in life through their care recipient. This is illustrated by Mrs C: "*Knowing that someone cares back when you're sad and appreciates what you do, gives meaning to caring and makes things seem more worthwhile"*.

Socio-Cultural

A prevailing theme was the socio-cultural impact imposed on carers' lives as a result of their caregiving experience. This theme highlights the social isolation experienced by carers, as well as the obligation that guided carers to perform their role.

Socially isolated. Social isolation appeared in discussions about loss of companionship, loss of friends and family relationships, as well as loss of social activities. Statements of carers, which represented isolation from social activities included: *"Social life is very hard", "It's very hard because I used to socialise with a lot of people",* and *"Well, it's stopped me going out a lot".* The most significant reason that carers gave for reducing their social activities was that engulfment in their caregiving role had left little time to attend personal needs.

It was common for spousal carers to identify their spouse as their main source of social support and socialisation before they took on the caring role. Thus, isolation was a consequence of the failure of these components in their relationship to continue. According to one spouse:

> *I feel the loss in as much that we can't do the things that we used to. We used to love walking along the beach and holding hands. He used to have a wonderful sense of humour and we always used to be doing stupid things. You miss the closeness of it all. You miss the fun. There is no fun now. In fact, I was very concerned about eighteen months ago because I felt my whole personality was being killed.*

Another spouse described this further: "*Emotionally, all of a sudden you know, he was the centre of the universe and making him happy was everything. Everything revolved around him*". In spousal carers, isolation resulted from lost companionship, relational deprivation, and changes in the dyadic relationship. Isolation was further compounded by a lack of understanding from friends and family. Mrs H stated:

> *They don't understand. You know people say "Gee, your husband looks well". I say yeah, now look at me. So he should do. Who wouldn't look well when you don't have to do a thing? He gets the best care and he doesn't have to do a thing.*

Congruent with existing literature, spouses in the current study were more committed than other types of carers to providing all types of care themselves (Marks, Lambert, & Choi, 2002). Possible interpretations of this finding include that providing such intensity of care prevented spousal carers from using formal services (e.g., respite) out of fear that others may not perform the role as well as they would. Also, spousal carers had developed their identity based on both roles (e.g., spouse and carer), and as such, the meaning of caregiving tasks had become incorporated into their identity. Failure to perform all tasks would have thus resulted in negative self-concepts.

Coinciding with the stress proliferation theory, as caregiving demands increased so did carers' vulnerability towards additional stressors (Pavalko & Woodbury, 2000). Additionally, caregiving had become so overwhelming that some experienced a lost perception of personal wholeness and connections with others. According to Skaff and Pearlin (1992), this can lead to feelings of isolation. Mrs J described how remoteness to her grandchildren left her feeling isolated:

> *I didn't get to spend a lot of time with my family and grandkids. [Husband] would get tired and little boys hanging around is very tiring. And we didn't babysit as much as I would have liked. There were other people who were filling that role. My younger grandson is a bit remote with me and I wonder if that was because the other granny was always there and I was only there sometimes.*

Carers also reported how their isolation was exacerbated by factors related to societal views of ageing. In consonance with this, Mrs B stated:

> *Number one, you're over sixty five and no one gives a damn about you. Well, because you are in the aged care system, and to me, there is no care in the aged care system because it's one size fits all.*

Stigmatisation resulted in feeling abandoned by social support systems. For most of these carers, feelings of isolation were related to their own perceptions of the adequacy of support, rather than the amount of contact with others. Social isolation in older adults can result in an increased risk for dementia (Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000) and

mortality (Eng, Rimm, Fitzmaurice, & Kawachi, 2002). As many of the socially isolated carers in the current study lacked insight into their isolated condition and its ramifications, they were unlikely to actively seek assessment and treatment.

Socially and culturally obligated. In general, caregiving was discussed by participants in terms of an obligated adherence to constructed beliefs related to socialisation, reciprocity, indebtedness, and the enactment of familial duties. Furthermore, it reflected an adherence to traditional gender values. All woman expressed that "*it was the right thing to do*", and most felt that they had "*no choice*".

When questioned about why they took on the caregiving role, many revealed that they had been socialised as children to be carers. Mrs A articulated: "*It's my lack of ability to reach out. I think that's because we learnt as children.... I think that's because as children growing up, we cared for instead of being cared for*". Another carer expressed: *"I mean I've probably done caring most of my life"*. Coinciding with previous findings, carers had internalised norms regarding appropriate gender role behaviour (Harrington-Meyer, 1999). Most attributed characteristics such as *"compassionate"* and *"understanding"* to themselves. These characteristics reflect emotional work that is typically carried out by women (Gonyea et al., 2008). Carers also believed that they were the family "kin keepers" and that responsibility to preserve and nurture family connections fell to them. Duty and obligation as a motivating factor in the decision to care was often a dark side of familial caregiving. Mrs D revealed:

> *It was never an option, no. It doesn't matter whether I'm upset or what injury I've got, I'd still be looking after him. Yes, because I know the other brothers and sisters won't. Somebody's got to do it. I'm stuck with him and that's it. End of story.*

Mrs D was not alone in her predicament of being the only available carer. When carers believed that there was no one else to share the caregiving responsibility, they were likely to

compare their input to others, believing that the situation was unfair. Many described themselves as being the "*only one*".

Carers also described a sense of familial obligation and reciprocity that was so powerful that it subordinated their own needs. There are similarities in findings between the present study and those described by Losada et al. (2010). For instance, a sense of familism was not always protective against these carers' health. In fact, for some, it reinforced the social expectation of female carers to be self-abnegating and committed to duty. Mrs E echoed this sentiment:

> *I'm not sure about being valued. I think he thinks that's my job. That's my job. It always has been. My job is to look after the kids, look after this and that, you know. But that again is the age. You know, it's always been that way in that era. That the wife does everything and the husband just sort of does whatever he feels like doing.*

Daughter carers felt obligated to provide care out of a sense of indebtedness for all that their parents had done. Mrs F expressed: "*They've always been there and they've always helped us. So you know, it's our turn to help them*". Caregiving for parents was described as a "universal truth", similar to the construct of filial piety. Consistent with Chee and Levkoff's (2001) findings, these carers were unwilling to access respite services out of fear of being criticised by others for not fulfilling their filial duty. This is an important finding because it provides an understanding and knowledge of the various cultural needs and expectations of informal carers who are ageing in Australia.

Spousal carers were also overcome by feelings of indebtedness. Despite the inherent strains that accompanied caregiving, most spousal carers rejected the idea of abandoning their ill spouse. Mrs H expressed:

> *When you go into this role you've just got to understand that this is your lot. If you care about the person that you are caring for then you don't really have any choices. But if you don't, if you haven't got a good relationship with him or you don't care about them, then you do have choices. You just put them into a home. But I couldn't do that.*

Because carers felt indebted to their care recipient, caregiving was viewed as a form of repayment. An interesting finding was that carers calculated how they were repaying the care recipient. For instance, carers spoke of repayments in the form of missed opportunities for marriage, abandoned travel plans, and lost relationships with friends and family. Carers aimed to reduce their feelings of indebtedness to the care recipient by making sacrifices to take care of them. The greater the sacrifice (repayment), the less indebted they felt.

Although carers felt obligated to provide care, they were also satisfying their own emotional needs. This motive was inferred, rather than explicitly stated. Mrs C explained: *"If he wasn't a nice person it probably would be easy for me to say that it's too hard. But he is nice and he's done so much for me, so it's rewarding in that way"*. This was reiterated by another carer: "*You know, I then think what would I do if she wasn't there? I'd have to find someone else to care for because that's the sort of person I am"*.

These carers demonstrated a profound need to help others and they satisfied their emotional need for intimacy, reciprocity, and a loving connection. Spousal carers who maintain the loving continuity of their marital relationship are known to experience greater gratification from caregiving (Motenko, 1989). In contrast to earlier findings, however, there was no evidence to suggest that spousal carers experienced more satisfaction in their caring roles compared to other types of carers (Bien et al., 2007). It may be the case that the quality of the premorbid caregiving relationship and the carer's attachment style does in fact influence such outcomes. However, this remains beyond the scope of the present study.

Conclusion

The purpose of the current research was to investigate the perceived psychological impact of informal aged care via exploration of the lived experience of older female informal aged carers. Understanding carers' experiences in this context provides a vital perspective on the ways in which potential support systems can enhance carer outcomes. The current study

exposed carers' unique perceptions of caregiving, motivated by their willingness to help others understand the pleasures, anguishes, and challenges associated with their role. Oftentimes carers affirmed their dedication to caregiving by acknowledging positive aspects of their role, such as the discovery of a greater sense of meaning in life and a profound need to help others. However, for many carers, the positive aspects of being an informal aged carer were shrouded by poor psychological outcomes. These included uncertainty, guilt, loss, entrapment, social isolation, as well as social and cultural obligation. In several cases, these carers reported having experienced these outcomes at great frequency and magnitude.

Potential limitations of the current study relate to the sample. A few participants were recruited via an organisation that provides support to informal carers. To date, it is uncertain whether those who seek help from support services are more likely to suffer greater psychological distress than those who do not (Gonyea et al., 2008). Nonetheless, this does not negate the significance of the findings of the current study. The sample was varied and participants' rich descriptions allow readers to consider the transferability of findings to their population.

Although many carers did not explicitly identify psychological needs, their needs were reflected in their narratives. The findings identified that it is important for health care professionals to identify circumstances under which negative caregiving outcomes might be more pronounced. The challenge is to then develop individualised care strategies that would meet carers' unique needs. Strategies may involve the provision of information, as well as teaching carers problem-solving strategies to help manage stressors. Health care providers could also focus on carers' sense of meaning as they develop supportive partnerships with carers. Additionally, in order to improve informal carers' access to mental health services, a government run program should be developed offering home-based mental health assistance. At present, this does not exist. This program should be nationally consistent, but adapted to

suit local circumstances. Most participants expressed that access to such services would only be made possible in their own homes due to restrictions imposed by time constraints and caregiving responsibilities.

Future researchers may wish to follow up carers' experiences with a longitudinal study exploring how experiences change throughout the caring trajectory. As service needs change, so too may the needs of the carer. It is also important to research informal aged carers' experiences across different cultures and socio-economic groups within Australia, because research suggests that such factors can influence overall wellbeing (Vellone et al., 2011). Additionally, the findings of the current study could help lay the foundation for the development of a quantitative measure with which to assess and monitor informal aged carers in Australia.

Furthermore, it is discouraging to note that few psychologists in Australia work with this portion of the population. Future research may also wish to explore the role of psychologists in this cohort as there is evidence that psychological treatments, such as cognitive behaviour therapy, are effective in older populations (Koder & Helmes, 2006). This would assist psychologists to be better prepared to meet older carers' needs.

In conclusion, in a time when female informal aged carers are providing a significant portion of aged care, it is important that researchers hear their perspectives of their caregiving experiences. This will enable opportunities to identify circumstances under which negative outcomes might be more pronounced, and to determine areas to consider on intervening. The current study further affirms the psychological impact of the caregiving experience on the mental health of informal aged carers, and provides impetus for significant and prompt change in social valuing and policy.

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Appendix A

Demographic Characteristics of Participating Informal Aged Carers

	Mrs A	Mrs B	Mrs C	Mrs D	Mrs E	Mrs F	Mrs G	Mrs H	Mrs I	Mrs J
Age	69	71	65	65	76	65	72	76	72	71
Gender	F	F	F	F	F	F	F	F	F	F
Marital Status	Single	Single	Married	Single	Married	Single	Single	Married	Single	Widowed
Relationship to Care Recipient	Sister (Sister)	Daughter (Mother)	Wife (Husband)	Daughter (Father)	Wife (Husband)	Daughter (Mother & Father)	Friend (Friend)	Wife (Husband)	Sister (Brother)	Wife (Husband)
Care Recipient Ailment	Physical/mental illness	Physical	Physical/heart problems/mental illness	Physical/heart problems	Parkinson's disease	Dementia/physical	Physical/mental illness	Parkinson's disease/diabetes	Dementia	Parkinson's disease/stroke
Living with the Care Recipient	No	No	Yes	Yes	Yes	No	No	Yes	No	Yes
Years Spent as a Carer (±7)	+7yrs	+7yrs	+7yrs	+7yrs	-7yrs	-7yrs	+7yrs	-7yrs	-7yrs	-7yrs

Appendix B

Participant Informed Consent Form

Project title: An Investigation into the Psychological Impact of Informal Aged Care via Exploration of the Lived Experience of Older Female Informal Aged Carers

Contact Details

Student Researcher:	Emma Stein
Faculty and School:	School of Psychology and Social Science (Edith Cowan University)
Research Supervisor:	Dr Eyal Gringart
Phone:	(61 8) 6304 5631
Email:	e.gringart@ecu.edu.au
Faculty and School:	School of Psychology and Social Science (Edith Cowan University)

Consent:

If you have read the details in the information letter explaining the research, and are interested in participating in the study, please indicate this by signing the statement below.

I have been given the research information letter and I understand the purpose of the study and what I would be required to do as a participant. I understand how my provided information will be used, and that it will only be used for the purpose of this research project. I have been given the opportunity to ask questions and any questions have been answered to my satisfaction. If I have any additional questions, I am aware that I can contact the research team.

I understand that participation in the research project will involve an audio recorded interview and that the tape will be erased at the completion of the study. I understand the information provided will be kept confidential and that my identity will not be disclosed without consent. I also understand that I am free to withdraw from further participation at any time, without explanation or penalty.

Given this information, I freely agree to participate in the research project.

Participant's Name: _____

Participant's Signature: _____ **Date:** _____

Researcher's Name: _____

Researcher's Signature: _____ **Date:** _____

Appendix C

Participant Information Letter

Project title: An Investigation into the Psychological Impact of Informal Aged Care
via Exploration of the Lived Experience of Older Female Informal Aged Carers

Researcher: Emma Stein
Research Supervisor: Dr Eyal Gringart

My name is Emma Stein and I am a student in a Bachelor of Arts (Psychology) Honours
degree at Edith Cowan University (ECU) in Perth, Western Australia. You are invited to take
part in this research project which I am conducting as part of the requirements for my degree.
The research project has ethics approval from the School of Psychology and Social Science
Ethics Sub-Committee.

The project aims to explore the experience of female informal aged carers who are between
the ages of 65-75. This would assist in supporting informal carers in their caregiving roles, as
well as further the knowledge base for guiding and informing contemporary health and social
policy.

If you choose to take part in the project you will be asked to participate in an audio recorded
interview conducted by me. The interview will take place at a location that is suitable for you
and I, and it will take approximately one hour. All information collected during the interview
will be treated confidentially and will be coded so that you remain anonymous. All data
collected will be stored securely on ECU premises for five years after the project has
concluded, and will then be confidentially destroyed. The information will be presented in a
written report, in which your identity will not be revealed. You may be sent a summary of the
final report on request.

The topics that will be discussed centre around your experience as an informal aged carer,
how you cope with this, and the types of support that you receive and require.

In the event that some discussed interview issues become emotionally upsetting, I have
provided the following details of free counselling services for you to use as you wish.

    Carers WA Helpline: 1800 242 636 (free-call)
    Crisis Care Helpline: 1800 199 008 (free-call)
    Beyond Blue Helpline: 1300 224 636

Your contribution to this research will be greatly valued and will help to contribute to a
greater understanding of the needs and experiences of female informal aged carers. It will
also offer a sound basis for improving future policies and service responses.

Participation in this research is voluntary and you are free to withdraw or refrain from
answering any questions at any time. There will be no penalty for doing so.

If you have any questions about the research or require further information, you may contact the following:

Student Researcher:	Emma Stein
Faculty and School:	School of Psychology and Social Science (Edith Cowan University)
Research Supervisor:	Dr Eyal Gringart
Phone:	(61 8) 6304 5631
Email:	e.gringart@ecu.edu.au
Faculty and School:	School of Psychology and Social Science (Edith Cowan University)

Should you have any concerns regarding this research and you would like to contact an independent research ethics officer, you may contact:

4th Year Coordinator:	Dr Bronwyn Harman
Phone:	(61 8) 6304 5021
Email:	b.harman@ecu.edu.au

Thank you for your time.

Kind Regards,

Emma Stein

Appendix D

Interview Schedule

1. Can you please tell me about informal aged care in your life?

    a. Relation to aged person?

    b. How long have you been an informal carer?

2. Can you please share with me any effects that this role may have had on your life?

    a. Time factors/social life/family/health?

    b. Behaviours/feelings/thoughts?

3. Can you please tell me about any informal support that you are getting as an informal aged carer?

    a. Social/emotional/physical/financial support?

    b. Where has this support come from?

4. Can you please tell me about any formal support that you are getting as an informal aged carer?

    a. Social/emotional/physical/financial support?

    b. Where has this support come from?

5. What would be the ideal situation for you as an informal aged carer?

    a. Which factors would be most important?

    b. How do you feel that this situation would affect you and the care recipient?

6. Are there any other relevant things related to informal aged care that you can share with me?

    a. Age factors/concerns/improvements/rewards/challenges?