

**ASSESSING CAREGIVERS' HOPES AND EXPECTATIONS FOR RESPITE CARE**

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### Abstract

**Background.** While the provision of respite care is a well-known strategy for supporting caregivers of persons with dementia (PWD), it is still unclear what influences its use by caregivers. **Objective.** To explore respite care use through the lens of a hopes and expectations framework. **Methods.** Six caregivers of PWD took part in one semi-structured interview. A phenomenological approach to data collection and analysis was employed. **Results.** The data showed that caregivers still felt burdened despite utilizing respite care. Hopes and expectations for the PWD tended to converge for all caregivers, yet diverged depending whether they were considering impact on themselves or the PWD, and whether they had used respite care or not. **Conclusion.** Preliminary data suggests that respite care services may need to focus more on helping caregivers. The framework of hopes and expectations is useful for exploring the use or non-use of respite.

*Key words:* Dementia; Caregivers; Respite Care; Hopes; Expectations

### Résumé

**Contexte.** Les services de répit sont une source de soutien bien reconnue pour les proches aidants de personnes atteintes de démence (PAD), mais les raisons pour lesquelles ils y font recours restent à explorer. **Objectif.** Décrire le phénomène de l'utilisation des services de répit du point de vue des attentes et espoirs. **Méthodes.** Six proches aidants de PAD ont participé à des entrevues semi-structurées. Une approche phénoménologique a été utilisée pour la cueillette et l'analyse des données. **Résultats.** Les proches aidants ressentent un fardeau malgré l'utilisation de services de répit. Les attentes et espoirs qu'ont les proches aidants vis-à-vis la PAD convergent, mais divergent lorsqu'il s'agit de l'impact sur eux-mêmes, et ce, selon l'utilisation qu'ils font du répit. **Conclusion.** Les résultats préliminaires suggèrent que les services de répit pourraient davantage mettre l'accent sur les proches aidants. Le cadre conceptuel des attentes et espoirs facilite l'exploration de l'utilisation des services de répit.

*Mots clé:* démence; aidants naturels; répit; espérances; attentes

## **Interdisciplinary Relevance**

The present study explores the issue of health service use or non-use by examining hopes and expectations of caregivers. While this research focuses on the use of respite care by caregivers of people with dementia in particular, the model of hopes and expectations can be used to better understand the use or non-use of health services and the identification of priorities in a variety of different fields. Individuals' hopes and expectations may play an important role in the decision-making process and could be integrated into tools to assist in this process, whether it is the decision to use, continue using, not use, or stop using respite care or other health services, community-based or otherwise.

Furthermore, dementia entails particular challenges, which require an interdisciplinary approach. Not only does the disorder manifest itself through a broad range of physiological and psychological symptoms, but some or all of these symptoms worsen over time. Because of this, healthcare professionals from a variety of disciplines will be called upon at some point throughout the trajectory to help facilitate the many transitions that will be faced. Furthermore, an understanding of the impact of the disease itself can help understand how and why caregivers of people with dementia have been demonstrated to experience more serious health declines when compared to other caregivers. The study of caregiving in dementia may therefore appeal to a wide audience of researchers who are interested in conditions which result in some or all of the identified repercussions of dementia care, be they the impact of memory or attention or other functional limitations which affect activities of daily living.

## **CHAPTER 1: INTRODUCTION**

Dementia, now referred to as major neurocognitive disorder in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), is characterized by marked cognitive decline, observable not only by the individual but also by others and through assessment tools (American Psychiatric Association [APA], 2013). This cognitive decline can be noted in a variety of domains, namely language, attention, memory, social cognition, learning, and perception (APA, 2013). In order for a diagnosis to be made, these deficits must be marked enough to impede an individual's ability to engage in complex everyday activities (APA, 2013). The disorder stems from varied aetiologies, the most common of which are Alzheimer's disease and vascular events, which most often occur in individuals aged 65 years or older (Azad, Al Bugami, & Loy-English, 2007).

According to census data, 14.8% of Canadians were aged 65 years or older in 2011 (Statistics Canada, 2013). The proportion of Canadians aged 65 or older is projected to increase to nearly one in four as the youngest members of the baby boomer generation reach this age by the year 2036 (Statistics Canada, 2013). The aging of the Canadian population will bring with it an increase in the incidence of dementia (Alzheimer Society of Canada [ASC], 2010). The incidence rate was 103,700 new cases per year in 2008, and it is predicted that it will increase to 257,800 new cases per year by 2038 (ASC, 2010). Alongside this rise in the incidence of dementia, there is and will continue to be a shift away from long-term institutional care towards more home- and community-based care (ASC, 2010).

In 2008, approximately one in four individuals with dementia were living at home and receiving only informal care from their family or friends who have taken on a caregiver role

(ASC, 2010). In 2008, Canadians spent roughly 231 million hours providing informal care, with the care provided by family members falling within this category (ASC, 2010). In order for Canadians with dementia to remain in the community, at home, the reliance on informal caregivers will necessarily grow (ASC, 2010). Conversely, in order for caregivers to maintain their roles and keep the individuals for whom they care outside of the institutional setting, they also need to maintain their own health, both physical and mental.

### **1.1 Caring for a Person with Dementia**

Caring for an individual with dementia is an extremely challenging role to adopt (Phillipson and Jones, 2011). Måvall and Thorslund (2006) reiterate this by remarking that “being related to someone with dementia changes one’s life completely” (p. 137). When a person with dementia is living in the community rather than in an institutional setting, the onus of caring is placed entirely upon an informal caregiver who, most often, is a family member (Conlin, Caranasos, & Davidson, 1992).

Caring for a person with dementia is a complex and all-encompassing task. Caregivers are typically charged with taking on a variety of instrumental activities of daily living (IADLs) and activities of daily living (ADLs), depending on the progression and severity of their loved one’s dementia (Pinquart & Sörensen, 2003). IADLs, on the other hand, are those tasks which are not fundamental to daily life, but which are necessary for independent living, including financial management, ensuring proper medication consumption, cooking and housework, transportation, and shopping (Pinquart & Sörensen, 2003). ADLs are those self-care tasks which are fundamental to everyday functioning, such as bathing, grooming and dressing,

feeding, and basic mobility (Pinquart & Sörensen, 2003). Depending on the progression of the individual's dementia, the caregiver may be charged with some or all of these tasks, and is likely to forego his or her own hobbies and pleasurable activities in favour of completing these important tasks (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). It is important to highlight the fact that dementia progresses in such a way that there are continual and changing “cognitive, behavioural and affective losses,” and caregivers tend to continue providing care throughout much of this progression, rarely relinquishing their roles outside of dire circumstances (Ory et al., 1999, p. 177). In other words, once an individual takes on the role of caregiver, there is an understanding that the condition of the person with dementia will never improve and that the caregiver will bear witness to the decline as it occurs (Ory et al., 1999).

The experience of being a caregiver and the impacts associated with the role may vary depending on several individual factors. In general, spousal and child caregivers tend to provide more care than other relatives or friends, the latter normally taking on a secondary caregiver role (Dupuis, Epp, & Smale, 2004). When compared to one another, spousal caregivers tend to provide care for a longer period of time (Dupuis, Epp, & Smale, 2004). Spouses and daughters in particular appear to dedicate more time to caregiving, to engage in a broader range of caregiving activities, and are more likely to take charge of classic care activities, such as activities of daily living (Dupuis, Epp, & Smale, 2004). The fact remains that caring for a family member living with dementia is no small feat, and can have a variety of physical and psychological impacts on the caregiver (e.g. Chatillon et al., 2013; Goode et al., 1998; Kim, Chang, Rose, & Kim, 2011; Mahoney, Regan, Katona, & Livingston, 2004; Ory et al., 1999; Pinquart & Sörensen, 2003).

An important impact of being a caregiver is caregiver burden, which is very well documented in the literature (di Mattei, Prunas, Novella, Marcone, Cappa & Sarno, 2008; Etters, Goodall, & Harrison, 2007; Goode et al., 1998; Kim et al., 2011; Lee, 1999; Lin, Tsai, Wang, Hwang & Fuh, 2012). It is defined as a “multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” (Kim et al., 2011, p. 846). As noted by Goode et al. (1998), this stress can emerge for a variety of reasons. Taking on a direct patient care role involves helping the individual with the ADLs and IADLs discussed above, which is a great source of stress (Goode et al., 1998). Another important source of stress lies in the behavioural changes that can occur (Goode et al., 1998). The caregiver is left to cope with a wide variety of behaviours, such as wandering, verbal or physical behaviours and repetitive questioning which are often perceived to be disruptive, leading to increased levels of stress (Goode et al., 1998). While some of these may be related to the neurodegenerative changes in the brain such as loss of function of the frontal lobes, it is now believed that that many behaviours can be triggered by environmental changes and cues (Dupuis, Wiersma & Loiselle, 2012).

Caregiver burden can be divided into two categories, namely objective and subjective burden (Pinquart & Sörensen, 2003). Objective burden refers to the practical consequences of the changes in the person being cared for as well as events related to negatively perceived caregiving experiences, while subjective burden refers to the emotional response to caregiving and its various implications (Pinquart & Sörensen, 2003). Objective burden, for example, could result from a person with dementia developing the tendency to wander or losing the ability to bathe oneself, in which case the caregiver will need to make new arrangements and take on more responsibility (Pinquart & Sörensen, 2003). Subjective burden on the other hand,

might be the emotional and psychological response to these troubling events, manifested in anxiety, stress, depression, and sadness (Pinquart & Sörensen, 2003). Typically, a global measure of caregiver burden, such as the Zarit Burden Interview, is used to capture both the objective and subjective facets of burden (Pinquart & Sörensen, 2003).

Caregiving is also associated with a decrease in mental health. Caregivers of people with dementia are prone to experiencing higher levels of psychological morbidity, as well as depression and stress, as compared to non-caregivers and individuals who care for physically ill or injured relatives (Brodaty & Hadzi-Pavlovic, 1990; Eagles, Craig, Rawlinson, Restall, Beattie & Besson, 1987; Livingston, Manela, & Katona, 1996; Mahoney, Regan, Katona, & Livingston, 2004; Pinquart & Sörensen, 2003). They report elevated levels of depressive symptoms and anxiety, and tend to use health services and psychotropic medications more frequently than their non-caregiving counterparts (Mohamed, Rosenheck, Lykestos, & Schneider, 2010). Lowered affect, sadness, and loss of energy are among the symptoms frequently reported by caregivers of people with dementia in particular (Pinquart & Sörensen, 2003; Mausbach, Patterson, & Grant, 2008). Mausbach, Patterson, and Grant (2008) found an association between the extent to which caregivers restrict their own activities – typically pleasant ones revolving around leisure or socialization – and depressive symptoms.

Caregivers of people with dementia are also at risk for poorer physical health. Caregivers have been found to be at risk for hypertension which, in turn, is a risk factor for cardiovascular disease (Chatillon et al., 2012). Indeed, Capistrant, Moon, Berkman, and Glymour (2012) found that caregivers were 35% more likely to develop cardiovascular disease than non-caregivers. Among women, those who are caregivers have been found to be twice as likely to develop coronary heart disease (Lee, Colditz, Berkman, & Kawachi, 2003). These

cardiac conditions have been found to be related to the psychological distress experienced by caregivers (Moore et al., 2013). Much like the psychological symptoms listed above, increased blood pressure may also be associated with the caregivers' restriction of pleasant activities (Chatillon et al., 2012).

Caregiving appears to cause more negative impacts, both psychological and physical, among women (Pinquart & Sörensen, 2011). With regards to spouses, it remains unclear whether male spouses actually experience less distress as a result of providing care to a loved one or process and handle this distress differently than their female counterparts (Pinquart & Sörensen, 2011). The difference may be due to the individual's perception of the caregiver role, the different coping styles typically employed by either gender, or the impact of burden on the caregiver's perception of daily life (Dupuis, Epp & Smale, 2004). With regards to adult children, daughters appear to be more likely to take on a caregiver role than sons, and some literature suggests that daughters may experience more distress than their male counterparts due to the various and competing demands they may face – for instance, caring for an ill parent, caring for one's own children, and working inside or outside the home (e.g. Martin Matthews & Rosenthal, 1993). Conversely, some literature suggests that the presence of competing roles may be a protective factor, and that the differences between daughters and sons are better explained by their respective approaches to the caregiver role (e.g. Scharlach, 1994). While gender and relationship to the person with dementia may play a role in the experience of the impacts of caregiving, there remains a certain incongruence on this topic in the literature (Pinquart & Sörensen, 2011).

## 1.2 Respite Care

Respite care is “an arrangement to allow caregivers relief or ‘time-out’ from their care commitments, which may be provided on a regular basis or in emergencies” (Jeon, Brodaty, Chesterton, 2005, p.298). It can be provided in a variety of settings, including the home, at day centers, or institutional environments offering multiday and overnight stays (Lund, Utz, Caserta, & Wright, 2009). The provision of these services is grounded in the assumption that temporarily relieving caregivers of their duties will alleviate burden and maybe even allow the individual with dementia to remain at home, in the community, for a longer period of time (Gilmour, 2002).

Ideally, using a respite service would afford the caregiver the opportunity to be relieved not only of the physical demands of caregiving, but also the mental demands (Canadian Healthcare Association [CHA], 2012). One of the objectives of these centres is to provide caregivers with the opportunity to develop their own personal interests, pursue meaningful social activities, and enjoy an increase in quality of life, all without abandoning their relationship to the person being cared for (CHA, 2012).

In order for a respite experience to be perceived as positive, a feeling of trust between the primary caregiver and the formal care provider is essential (Greenwood, Habibi & Mackenzie, 2012; Phillipson & Jones, 2011; Rajan, 2008). More specifically, the caregiver must trust the individual care provider as well as the respite service in general (Greenwood et al., 2012). If a caregiver does not trust the person with whom they have left the individual with dementia, it will be extremely difficult to relax and enjoy their time away—and spend it doing things that they enjoy (Greenwood et al., 2012). Phillipson and Jones (2011) note that “access

to quality, trustworthy, and familiar staff to provide care strongly influenced caregivers' perceptions of the utility of home-based respite services" (p. 51). Whether a care worker is going into the home or the cared for is going into a care setting, this trust is imperative to the respite experience.

In order for caregivers to reap the potential benefits of respite care, they need to use the services available. The Canadian Healthcare Association (2012) notes several barriers to respite care use in their report. Among these are the fear that the caregiver will be perceived by others as being unable to cope, the feeling of guilt associated with seeking outside assistance, and organizational barriers, such as finances and systemic challenges, that make accessing services more difficult (CHA, 2012; Sorrell & Cangelosi, 2009). According to Statistics Canada, only 13% of caregivers aged 45 years and older sought support from the community, and only 12% sought support from the government (2007). Canadian caregivers in this age group tended to seek assistance from family members, close friends and neighbours before seeking help from government subsidized services, which includes respite care (Statistics Canada, 2007). Caregivers' hopes and expectations will be discussed below as a possible factor in this decision-making process.

### **1.3 Theoretical Framework: Formulation of Hopes and Expectations**

Hopes and expectations are an important facet of the care recipient's experience of a health service. Janzen, Silvius, Jacobs, Dalziel and Drummond (2005) note that there exists a certain degree of ambiguity and confusion in the literature surrounding what constitutes a hope and an expectation. They suggest that, despite conflicting claims in the literature, they are not

one and the same (Janzen et al., 2005). To clarify the distinction, Leung, Silvius, Pimlott, Dalziel, and Drummond (2009) note that while both “hopes and expectations are future-oriented cognitions, expectations are distinct in that they are an individual’s probability-driven assessment of the most likely outcomes, while hopes are an assessment of the most desirable – but not necessarily the most probable – outcomes” (p. 347). In more simple terms, the hope is the preferred outcome, while the expectation is the most probable outcome, as perceived and identified by a particular individual (Leung et al., 2009). In this context, probability is purely subjective rather than objective and numerical. It is also important to make the distinction that this discussion pertains to particularized hopes, those pertaining to specific situations and events, rather than generalized hope, which involves an individual’s overarching perspective and belief (Leung et al., 2009).

In their article, Leung et al. (2009) delineate a process by which hopes and expectations may be formulated and become differentiated from one another (Figure 1). They propose that this process occurs in three phases. First, the individual appraises the situation to determine what the possible outcomes are, and whether these outcomes should be considered hopes or expectations (Leung et al., 2009). Next, varied factors dictate the extent to which the individual perceives these outcomes as achievable, and strategies are developed and employed to increase the chance of hopes being achieved (Leung et al., 2009). Finally, the process ends with the individual employing these strategies and realizing these hopes; if the hopes were unachievable, the process may begin again and new hopes and expectations may be identified (Leung et al., 2009). The phases of this process are discussed in greater detail below.

### **1.3.1 Appraisal of possible outcomes**

In the *appraisal of possible outcomes* stage, the individual is appraising a situation and identifying which outcomes may occur given the situation (Leung et al., 2009). The factors involved in this phase include optimistic bias, precipitating phenomena, and the individual's prior knowledge of the phenomenon or situation being appraised (Leung et al., 2009). Optimistic bias refers to an individual's overestimation of the likelihood of an ideal outcome being achieved, paired with an underestimation of the probability of a negative outcome occurring, and presents with a near complete convergence of hopes and expectations (Leung et al., 2009). The less desired outcome may be slightly or even very likely to occur, but an individual displaying optimistic bias does not perceive it as such. An example, here, may be that a caregiver using respite care perceives that their loved one will enjoy the activities during the first respite session, while underestimating the reality that there may be an adjustment period during which their loved one acclimates to the new setting.

In this model, a precipitating phenomenon refers to an event that initiates the process of formulating hopes and expectations, presenting as a challenge to the individual's optimistic bias (Leung et al., 2009). An event "may act as a precipitating phenomenon if it entails some level of subjective risk to a specific aspect of an individual's optimistic cognition" (Leung et al., 2009, p. 353). An example of a precipitating phenomenon in this context may be that the caregiver has suddenly fallen ill and requires assistance in the care of their loved one while they regain their health, or that there is a particular event that the caregiver would like to attend, requiring that they plan for alternate care during that timeframe. Many factors may

incite the use of respite care, such as the feeling of being unable to cope without outside support and needing a break.

Finally, an individual's prior knowledge, including past experiences and information gathered from others, is important in the formulation of and differentiation between hopes and expectations in that they impact the perceived likelihood of both positive and negative events occurring (Leung et al., 2009). With regards to respite care, one caregiver may have heard from another that a particular service provider is not as good as another, which would initiate the process of forming hopes and expectations that are more dissimilar.

### **1.3.2 Cognitive analysis**

The *cognitive analysis* phase involves the interaction of several factors leading to the development of strategies for realizing hopes (Leung et al., 2009). First, temporal proximity refers to the distance, in time, between the individual and the event that is being or will be experienced. Leung et al. (2009) note that when "feedback (i.e. the event that can confirm or disconfirm hopes) is in the distant future, people may be better able to maintain hopes" (p. 355) or the belief that they are more probably achievable, compared to events that are more imminent. The temporal proximity between a caregiver and their eventual use of respite care may be such that an individual is currently using it, is in the process of obtaining the approvals necessary to use it, or may never have thought about using it.

Controllability, another important aspect, refers to an individual's ability to modify the outcome through his or her own actions (Leung et al., 2009). In the case of events with low controllability, the individual is forced to rely on external resources, among other things, to increase the likelihood of the desired outcome occurring (Leung et al., 2009). External

resources refer to those extrinsic factors that an individual can draw on, such as family members and friends, which provide interpersonal connection and social support (Leung et al., 2009). The presence “and quality of these resources may affect the perceived probability of hope realization,” (Leung et al., 2009, p. 355) leading the individual to believe that his or her hopes are more likely to occur.

The next variable in the model represents the goals set by the individual, which may contribute to the maintenance of hopes (Leung et al., 2009). When these goals are short-term, situation-appropriate, specific and realistic, they may have the ability to “empower an individual, and maintain the perceived likelihood of hopes being sustained” (Leung et al., 2009, p. 355). In the context of the present study, a caregiver may have a short-term, appropriate goal of engaging in a social event on a bi-weekly basis; on the other end of the spectrum, a caregiver may set the goal of having the freedom to engage in social activities or events whenever they please. The former is more likely to promote convergence of hopes and expectations and the maintenance of these hopes, while the latter is more likely to do the opposite.

Affect, an individual’s emotions, also plays an important role in the *cognitive analysis* phase (Leung et al., 2009). Negative affect in particular – in the case of depressed mood, for example – can contribute to reduced maintenance or achievement of hopes, in turn increasing the divergence between hopes and expectations (Leung et al., 2009).

Leung et al. (2009) suggest that “agency (a product of self-efficacy expectancies) and pathways (a product of behaviour-outcome expectancies) interact specifically with each other to produce behaviours which tend in favour of a preferred outcome,” (Leung et al., 2009, p.

356) and minimize the divergence between hopes and expectations. In other words, an individual's perceived ability to act in a situation, coupled with the identification of appropriate paths for action, may increase the likelihood of the individual achieving their ideal outcome (Leung et al., 2009).

### **1.3.3 Goal pursuit**

The final phase is that of *goal pursuit*, in which the individual employs the strategies identified in the previous stage to realize his or her hopes (Leung et al., 2009). If the strategies decided upon through cognitive analysis do not prove to be useful, further cognitive analysis may take place (Leung, et al., 2009). Further, if the hope remains unattainable, the process may begin again and new hopes and expectations may be formulated (Leung et al., 2009). The present study focuses more on the formulation of and differentiation between hopes and expectations, as well as the level of convergence of divergence between these, rather than whether or not they are met. As such, the first two phases of Leung et al.'s theoretical model will be of special importance throughout the rest of this text.

## **1.4 Hopes and Expectations for Respite Care**

The literature on hopes and expectations in relation to health services – respite care in particular – remains under-developed, but a few examples are worth discussing. In their study, Neville and Byrne (2007) set out to assess the expectations of home caregivers (n=100) and formal care providers (n=25) of older people, a third of whom had been diagnosed with dementia, with regards to respite care. In this assessment, a hierarchy of expectations emerged

(Neville & Byrne, 2007). They identified that “the leading expectation for residential respite care was that the [...] care recipient would be well cared for” by skilled staff (Neville and Byrne, 2007, p. 28). The next top expectations for caregivers were that the cared for would be happy, would have opportunities to socialize, and that current health status would be maintained (Neville and Byrne, 2007).

Inherent to Neville & Byrne’s (2007) study is the notion of trust. The majority of the expectations necessarily rely upon the trust the caregiver has that the appropriate level of care will be provided (Neville & Byrne, 2007). Being that an expectation is probability-driven, one cannot reasonably expect that an individual will be perceived to be “well taken care of” without a strong sense of trust at the core of the care relationship. The interaction between trust, hopes and expectations will be an important one to explore.

On their end, Jurgens, Clissett, Gladman and Harwood (2012) found expectations to be important in caregivers’ perceived dissatisfaction with hospital care. These caregivers of people with dementia expected the hospital to employ a personalized style of care; however, they were met with the reality that acute hospital wards are extremely busy, and that staff cannot always focus on individuals (Jurgens et al., 2012). While not directly tied to respite care, these are important findings to consider. In their study, they found that expectations were unrealistic, not considered by staff, and often left unmet (Jurgens et al., 2012).

Jurgens et al. (2012) also found that caregivers, for instance, expected that the care relationship be seen as a triad rather than a dyad, such that the family caregiver continue to be an active member of the circle of care (Jurgens et al., 2012). It is easy to hypothesize that not creating this partnership could challenge the trust caregivers would have for the care team.

These findings, when viewed through the lens of Leung et al.'s (2009) framework, bring into question the use of the term 'expectation': it is not clear, here, whether the authors are discussing caregivers' hopes or expectations for hospital care.

With regards to residential respite care in particular, Phillipson and Jones (2011) found several beliefs that were tied to the use and non-use of respite by caregivers of people with dementia. Some caregivers reported feeling that service providers could not provide the same level of care that they themselves could, since these service providers would not have the same intimate knowledge of the person with dementia (Phillipson & Jones, 2011). For others, there was a firm belief that the use of residential respite care would yield negative outcomes and experiences, and that these would ultimately make caring for their loved one more difficult (Phillipson & Jones, 2011).

Conversely, Phillipson and Jones (2011) found a different set of beliefs among those caregivers who did use residential respite care. Among these caregivers was the belief that a break was necessary for them to continue to care for their loved one and, beyond that, to continue to provide the high level of care that they knew was necessary (Phillipson and Jones, 2011). In addition, some caregivers reported that they view respite care as better than full institutionalization, which, to them, would be the worst possible outcome (Phillipson and Jones, 2011). These beliefs can be reconceptualised as hopes and expectations using Leung et al.'s (2009) definitions. Among the caregivers who chose not to use respite care, there was an expectation that the use of such a service would lead to a negative outcome. They expected that residential respite care would make their lives more difficult and would not be good enough for the person for whom they care (Phillipson and Jones, 2011). There was no explicit

mention of hopes, nor was there a distinction between hopes and expectations, throughout this study.

Finally, Lund, Utz, Caserta, and Wright (2009) aimed to explore the extent to which caregivers' actual time use during respite care reflected their ideal desires for time use. Participants (n=25) were asked to report the approximate number of hours that they would like to spend doing a particular activity, such as spending time with family, exercising, or resting, followed by the number of hours they actually spent engaging in those activities (Lund et al., 2009). The authors then reported the degree to which these caregivers' desired time use and actual time use converged or diverged (Lund et al., 2009). It was found that 46% of their participants reported being somewhat or not very satisfied with their time use during respite, and these individuals tended to report elevated levels of burden and depression (Lund et al., 2009).

An alternative view, here, would be that the authors were seeking to discover the extent to which these caregivers' hopes for respite care time use were being met. In this case, though, there was no mention of the expected or most likely outcome with regards to time use. The present study sets itself apart in that it determines whether or not there are both or either hopes and expectations at play in the decision to use, continue using, stop using, or not use a respite service.

The literature cited above appears to use the term expectation without operationally defining it. Keeping in mind Leung et al.'s (2009) postulation of a process by which hopes and expectations are developed and differentiated, it becomes clear that certain of the expectations listed above may indeed be better described as hopes, particularly in the case of

Neville and Byrne's (2007) study. Building on Leung et al.'s (2009) work to further explore caregivers' hopes and expectations for respite care in particular, using fully operationalized definitions, will be an invaluable addition to the literature.

### **1.5 Summary**

It has been demonstrated that dementia has important consequences, both physical and psychological, on individuals who care for people with dementia (e.g. Pinqart & Sørensen, 2003). Respite care was specifically designed in response to these impacts; however, publically funded programs continue to be used by a minority of caregivers (CHA, 2012). A variety of factors, such as feelings of guilt for seeking help or the belief that the standard of care provided by respite centres is sub-optimal, lead to caregivers continuing to retain full responsibility for the care of their loved ones (CHA, 2012). These beliefs may be influenced by certain elements of Leung et al.'s (2009) conceptual framework, which attempts to explain the ways in which hopes and expectations are formulated as well as the reasons for which they may become differentiated from one another.

Expanding on these key concepts will make this an important addition to the literature. First, assessing caregivers' hopes and expectations in a clearly defined way, while placing them in opposition to each other, will contribute some clarity to the literature. Then, focusing on the caregivers' hopes and expectations for themselves, rather than only focusing on those for the person with dementia, will paint a more complete picture of the experience of using or not using such a service. The importance of trust has been discussed in the literature, and will also be an important factor to consider in the exploration of the use of respite care, and of

hopes and expectations in particular. Finally, contextualizing these themes within realm of decision-making give an otherwise theoretical study a practical edge, allowing for possible recommendations to emerge more clearly.

## **CHAPTER 2: RESEARCH QUESTIONS AND OBJECTIVES**

The purpose of the present study is to explore the roles of the hopes and expectations of caregivers of people with dementia in their decision to use or continue using, not use, or stop using respite care. The following research questions have been created to meet the goals of this research:

1. What are caregivers' hopes and expectations for respite care?
2. To what extent do caregivers' hopes and expectations play a role in their decision to use or not use respite care?

## **CHAPTER 3: METHODOLOGY**

### **3.1 Study Design**

This study was designed to explore what caregivers hope for and expect out of respite care, regardless of whether they have used such a service in the past, as well as the extent to which these played a role in their decision to use or not use such a service. It aims to describe and better understand the phenomenon that is the use or non-use of respite care by caregivers of people with dementia. Due to the inherently descriptive nature of this study, in-depth, semi-structured interviews were deemed the best method of data collection. A qualitative, phenomenological design and method of analysis was best suited to capturing the essence of the experiences described by the participants. Full ethical approval and certificate renewal were obtained from the University of Ottawa's Health Sciences and Science Research Ethics Board (Appendix A).

### **3.2 Recruitment**

At the outset of the study, the aim was to recruit six to eight participants. Participants were recruited with the help of the Alzheimer Society of Ottawa and Renfrew County, from support groups and programs run by the Society, and a private medical practice in Ottawa. Non-probabilistic sampling was aimed for, since the goal was “not to establish a random or representative sample drawn from a population but rather to identify specific [...] people who either possess characteristics or live in circumstances relevant to the social phenomenon being studied” (Mays & Pope, 1995). Variability among participants allows for a description of a common phenomenon from a variety of different perspectives (Mays & Pope, 1995), thus

increasing the richness of the data collected pertaining to the role of hopes and expectations with regards to this phenomenon. The goal had been to recruit caregivers holding different characteristics – namely gender and relationship to the person with dementia. That being said, participant recruitment proved to be challenging due largely to time constraints. While recruitment strategies focussed on obtaining some variability noted amongst the individuals sampled, the sample was ultimately selected for convenience. The perspective of a son caregiver would have been a useful addition to this study.

A flyer concisely outlining the study was distributed to individuals attending the venues listed above (Appendix B). In addition to a brief description of the project, the flyer contained a section in which prospective participants could write their name and email address or phone number. This contact information was returned to the primary investigator, who then made first contact with the potential participants. The primary investigator also provided a brief verbal presentation of the research project and distributed flyers at groups offered by the Alzheimer Society.

Once first contact was made, the participant was provided with more detailed information either verbally via telephone or by email, and was sent a letter of information summarizing what participation would entail and the inclusion criteria. If at this time the individual was interested in participating, a meeting was scheduled at the individual's convenience. At this meeting, informed consent was obtained, and potential participants were given the Mini-Cog (Borson, Scanlan, Chen, Ganguli, 2003) and Geriatric Depression Scale: Short Form (Yesavage, Brink, Rose, Lum, Huang, Adey, & Leiver, 1983) to finalize their inclusion in the study.

Individuals were deemed eligible to participate in the present study if they: 1) self-identified as the primary caregiver for a person with dementia, 2) scored negative on the Mini-Cog test (Borson, Scanlan, Chen, Ganguli, 2003), and 3) scored less than 5 on the Geriatric Depression Scale: Short Form (GDS), meaning they were not within the range normally considered for depressed mood (Yesavage et al., 1983). Participants signed a letter of informed consent prior to testing and, if appropriate scores were obtained, they were deemed eligible to participate and the interview was conducted. Individuals who spoke French or English and who had or had not used respite care were eligible to participate.

### **3.2.1 Testing for Exclusion**

Prior to being deemed eligible to participate and conducting the interview, participants were asked to take the two tests mentioned above: the GDS (Yesavage, et al., 1983; Appendix C) and the Mini-Cog (Borson, Scanlan, Chen, Ganguli, 2003; Appendix D). These tests were administered in order to exclude participants who may be overwhelmed by the potentially sensitive nature of the discussion, or whose responses may be coloured by possible cognitive decline or depressed mood. Letters to family physicians (Appendix D) were prepared in the event that one or more individual would score beyond the cut-offs listed below, to initiate a dialogue with their physician and explore the matter further. The participants were clearly informed that these tests were not administered as a means of diagnosis. All participants who consented to participate were included in the study, since none of them scored Positive on the Mini-Cog or >5 on the GDS.

*Mini-Cog.* This is a short cognitive test that “combines two simple cognitive tasks (three-item word memory and clock drawing) with an empirical algorithm for scoring”

(Borson, Scanlan, Chen, Ganguli, 2003, p. 1452). The Mini-Cog was found by Borson et al. (2003) to be effective in screening for dementia and cognitive impairment, much like the Mini Mental State Exam or other screening tools, while also being much faster to administer, which is why it was selected for use in the present study. Potential participants obtaining a positive score were deemed ineligible to participate (Figure 2).

*Geriatric Depression Scale: Short Form.* The GDS is a 15-item questionnaire designed to screen for possible depression in an older population (e.g. 65 years of age and older) (Yesavage et al., 1983). It was developed with the intention of avoiding issues related to screening for depression in older populations (for example, by ensuring that all questions are appropriate for individuals of advanced age, and using a yes or no format that is as easy to self-administer as it is to have administered by another) (Yesavage, et al., 1983). This particular depression screening tool was selected for its simplicity, ease of administration, and well-established reliability and validity (Yesavage, 1983). Potential participants scoring higher than 5 were deemed ineligible to participate.

While there was no minimum or maximum age for inclusion in the study, it was expected that most individuals would be older adults, which is why the GDS was selected for this component of the study. In the event of individuals younger than 65 years being interested in participating, the GDS was still deemed appropriate; Rule, Harvey, and Dobbs (1990) found that the GDS showed internal consistency and validity in a sample ranging from 17 to 55 years of age. As such, the GDS was kept as the measure for signs of depression rather than introducing a third instrument into the method of including or excluding potential participants.

Participants were recruited and categorized based on the characteristic of respite care use (Figure 3). Among caregivers who had never used respite care, there were those who did not want to and those who were thinking about it. Among caregivers who had used respite care, there were those who were currently using it and those who had used it in the past.

### **3.3 Data Collection**

After recruitment, each participant was assigned a code to de-identify any data collected and ensure anonymity. Data was collected through one in-person, semi-structured interview, occurring at the participant's convenience. Three of the interviews occurred in the participants' homes, two occurred at the Bruyère Research Institute, and one at the participant's place of work. The interviews were between 20 and 90 minutes in duration. Each interview was audio-recorded and transcribed for analysis.

An interview guide (Table 1) was designed to explore caregivers' hopes and expectations for respite care, and to ascertain whether these played a role in their decision to use or not use such a service. The guide outlined specific questions that were to be asked by the interviewer, but relevant deviations from the guide were welcome. In addition to this, the primary investigator wrote brief memos after each interview to determine whether or not any new elements should be introduced into the interview guide, and included notes on how to improve the interview process itself, as well as interesting details pointing to potential themes to keep in mind when it came time to analyze the data. The contents of the memos were not analyzed as such. Instead, they were used as a means of honing the interview guide and better determining when thematic saturation had been achieved. In short, these memos allowed for

a more seamless transition between data collection and analysis, and allowed the primary investigator to be more involved with the data in order to better understand the phenomenon while collecting more data. In the end, the only modification made to the interview guide was that offering definitions for both hopes and expectations to the participant before asking questions about either element individually.

The first section of the interview involved the gathering of demographic and general information about the participant to describe him or her. These questions gathered information about the participants' age, cultural background, living situation, employment status, relationship to the person with dementia, the type of dementia involved, their caregiving activities, and the types and quantity of social supports to which they had access.

Lincoln and Guba (1985) propose that credibility, the extent to which the results of a study make sense and are true, is an important tenet of rigorous qualitative methodology. Prolonged engagement with the research participant is one means of increasing a study's credibility (Lincoln & Guba, 1985). In the case of the present study, the interviewer had engaged with several potential participants in a community setting before they agreed to participate in the study. Here, rapport was built prior to the interview, leading in turn to conversations that were more likely to be genuine (Lincoln & Guba, 1985). While this proved to be an excellent method of eliciting meaningful conversations, it was not possible in two of six cases. For this reason, demographic and general information were gathered verbally at the beginning of the interview rather than through a survey. This allowed the participant and interviewer to discuss a variety of topics that were not strictly in response to the research questions; in other words, this first section of the interview acted as a form of rapport-building

to promote ease of discussion. Other elements of trustworthy qualitative research and data analysis in particular are discussed below.

In addition to this, the Zarit Burden Interview (Zarit, Reever, Back-Petersen, 1980; Appendix F) was administered as another means of describing the study participants and the perceived impact of their caregiving activities. The ZBI is a tool created to assess the level of burden an individual is experiencing, based on 22 yes or no questions (Zarit, Reever, Back-Petersen, 1980; Appendix C). This first section of the interview remained the same across all groups of participants.

The next part of the interview involved an exploration of the participants' knowledge of the respite services available to caregivers of people with dementia in Ottawa. It was essential to determine whether participants had not used a service due to lack of awareness or for other reasons. Here, the participants were asked to list and describe the respite services he or she was aware of. Next, the participants' hopes and expectations were explored through a series of open ended questions according to their current status of respite care use. The terms hope and expectation were defined before the participant was asked to discuss them, with the interviewer providing non-leading examples as necessary.

The final section of the interview involved debriefing the participant on the services available in Ottawa. This section was informed by the participants' knowledge of available services, as assessed in the previous section of the interview. This particular portion of the interview was not analyzed, unless elements from other parts of the interview came through or were brought up anew, since it consisted of the author providing information rather than gathering responses to questions.

The primary author (MA) transcribed the recordings verbatim after each interview, and verified the transcripts against their audio-recordings after some time had passed. MA and another student researcher (IK) both coded the interview data.

### **3.4 Data Analysis**

Qualitative data analyses can be done from a variety of perspectives, namely exploratory, explanatory or confirmatory approaches (Guest, MacQueen & Namey, 2012). In the case of exploratory analysis, a purely inductive approach, the content of an interaction between respondent and researcher is the driving force behind the development of codes and themes (Guest, MacQueen & Namey, 2012). Explanatory or conceptual analysis, on the other hand, combines inductive and deductive strategies, using existing literature and “previous work as a scaffold to explore the internal structure and dynamics of the concept” (Guest, MacQueen & Namey, 2012, p. 38). Finally, confirmatory analysis, a deductive approach, is used when the researcher wishes to test or assess a hypothesis or an idea (Guest, MacQueen & Namey, 2012).

The present study and its objectives make it a good candidate for explanatory analysis. On the one hand, the analysis is not entirely inductive, insofar as the design of the study and objectives were guided by Leung et al.’s (2009) model of hopes and expectations, which was used as a lens through which the researcher could view a particular phenomenon, in this case the use or non-use of respite care by caregivers (Guest, MacQueen & Namey, 2012). Similarly, the analysis is not entirely deductive, since the ultimate goal is not to test a particular hypothesis (Guest, MacQueen & Namey, 2012). As such, a combination of induction and

deduction – culminating in an explanatory analysis of the data – is without question the best fit for the study at hand.

While the major objective of this study was to identify what caregivers hope for and expect out of respite care, it was also critical to look in greater depth at participants' individual stories, perceptions and experiences, and the ways in which these nuance the data. For this reason, phenomenological analysis had initially seemed to be the most appropriate approach (Phillips-Pula, Strunk & Pickler, 2011). However, Leung et al.'s (2009) theoretical framework played a vital role in the creation and design of the study and data collection; elements of this model were integrated into the data collection tool and the author's intent was to use the model to guide data analysis.

### **3.4.1 Analytic Process**

Applied thematic analysis (ATA), as described by Guest, MacQueen and Namey (2012), was deemed the most useful and appropriate analytic technique to employ in this study. Because ATA's "primary concern is with presenting the stories and experiences voiced by study participants as accurately and comprehensively as possible" (Guest, MacQueen & Namey, 2012, p. 16) by combining elements of phenomenology and thematic analyses, it was selected for use in this study over other qualitative methods. The goal of the study was not to examine the use of language by caregivers when discussing their experiences with respite care, nor was the goal to develop a theory to explain why caregivers use certain services, for example, so discourse analysis and grounded theory were rejected as analytic approaches. ATA corresponded best to the aims of this study and was feasible given the type and quantity of data generated as well as the time allotted for analyses.

Guest, MacQueen and Namey (2012) identify several components involved in the applied thematic analysis: data segmentation, identification of themes, creation of a codebook, and coding. This is a process that may occur one or several times, and may be interrupted and restarted at any point.

Data segmentation involves the breaking apart of the data, in this case the interview transcripts, into smaller, more manageable units (Guest, MacQueen & Namey, 2012). In the case of structured or semi-structured interviews, as is the case in the present study, data segmentation can follow the order set out in the interview guide, keeping in mind that the content of a given discussion is liable to deviate from the guide (Guest, MacQueen & Namey, 2012). The successful qualitative analyst will ensure that, from beginning to end, a data segment contains adequate context, and will use these segments as a means of situating themes within the broader context without ignoring it (Guest, MacQueen & Namey, 2012).

In the present study, data segmentation was done in accordance with the topics covered in the semi-structured interview guide, which were selected to attempt to answer the research questions. MA performed an initial reading of the transcripts, demarcating these segments without attempting to code. The structural segments were:

- 1) Demographic and general information
- 2) Knowledge of available respite services
- 3) Hopes for respite care
- 4) Expectations for respite care

Data segmentation allows the analyst to discover themes within the data with ease. A theme is defined as “a unit of meaning that is observed [...] in the data by a reader of the text” (Guest, MacQueen & Namey, 2012). There are structural themes – those imposed by the design of the study and data collection instrument – and content themes – those emerging from the data independently of predetermined questions or topics (Guest, MacQueen & Namey, 2012). Structural themes are easy to identify, at once due to the aforementioned segmentation of the data and to the process of designing the data collection tool (e.g. one can expect to gather data pertaining to a particular theme when a question was asked regarding the topic at hand).

The identification of content themes, on the other hand, can occur in many different ways, as discussed by Ryan and Bernard (2003). The repetition of words or phrases within and between transcripts, depending on its relevance to the study’s objectives, participants’ transitions between topics, and the comparison of different segments within and between participants can all point to themes (Ryan & Bernard, 2003). During the reading of the transcript, Guest, MacQueen and Namey (2012) recommend flagging any and all potential themes, and reassessing throughout the analytic process to add or remove themes accordingly. The identification of these structural and content themes paves the way for the identification of codes and creation of a codebook.

The next level of data analysis involves coding. A code is defined as a piece of text that represents a portion or component of a larger theme (Guest, MacQueen & Namey, 2012). As noted in the discussion of themes, there are structural codes and content codes. The former are codes that necessarily emerge due to the design of the study, as was the case with structural themes (Guest, MacQueen & Namey, 2012). Content coding, on the other hand, refers to codes that emerge from the data independently of the predetermined interview topics (Guest,

MacQueen & Namey, 2012). The identification of codes occurs, once again, through close reading and re-reading of the interview transcripts, annotating “responses or descriptions that are similar; things that have cause-effect relationships; things that relate hierarchically or through webs of meaning; and disparate explanations of like events” (Guest, MacQueen & Namey, 2012). The codes identified through the reading of the present data were content codes rather than structural codes.

Once a tentative list of codes has been identified from within the transcripts, a codebook can be created (Table 2). A codebook is a list of codes that have been identified in the data, which may include interview question numbers and definitions depending on the types of codes being listed and can be shared with a second coder who will use it to code all the data, ideally without having seen it before (Guest, MacQueen & Namey, 2012). If inter-coder agreement is not reached between the two analysts, discussion may ensue followed by further adjustments to the codebook. Once the raw data is coded, data reduction can occur, in which the analyst organizes the coded data for presentation in the form of results (Guest, MacQueen & Namey, 2012).

MA created the codebook (Table 2), which was applied to the first three transcripts to verify that it fit the data well and did not leave any gaps. Level 3 in the codebook presents the content codes that emerged from the data. The codebook was then used to code the final three transcripts. After this, IK used the same codebook to analyze the transcripts without any prior knowledge of them. MA compared the transcripts she had coded with those coded by IK to determine whether the codebook was appropriate and whether there was any ambiguity in the coding. This was done to estimate the fit of the codes used rather than statistically calculate inter-rater agreement, thereby ensuring that no themes or codes were going unnoticed and

assessing whether codes could be combined to avoid redundancy. MA finalized the analysis by verifying all coded data. In reporting the results, MA re-read the transcripts to maintain an understanding of the whole.

The processes described above may create the impression the initial whole of the data is lost to the process of thematic analysis. While segmenting and identifying both themes and codes all yield smaller and smaller pieces of data, it is important to focus on linking them back to the whole throughout the analytic process, and using them to nuance the analysis (Guest, MacQueen & Namey, 2012). In this particular case, the author elected to include participants' individual stories – as similar or dissimilar as they may be from one another – in the format of rich vignettes, punctuated by the themes and codes identified throughout the analytic process, to lend colour and individuality to the analysis.

Data analysis occurred manually on physical copies of interview transcripts and electronically on Microsoft Word. While NVivo10 may have offered some convenience, it ultimately did not contribute to the process of data analysis.

### **3.4.2 Criteria for Rigorous Qualitative Research**

Assessing rigour may be perceived as being less straightforward in qualitative research than it is in its quantitative counterpart; the reality, though, is that different criteria must be used when assessing these types of studies (Lincoln & Guba, 1985). Lincoln and Guba (1985) note that the concepts of validity, reliability and generalizability, hallmarks of assessments of quantitative research, do not apply as neatly to qualitative inquiry; rather, a study's trustworthiness – its credibility, transferability, dependability and confirmability – are indicators of rigorous methodology (Lincoln & Guba, 1985), and are important at both the

levels of data collection and analysis. Credibility was discussed above, as it pertained most significantly to data collection. Transferability, dependability and confirmability, as they pertain to data analyses, are discussed here.

Transferability alludes to the extent to which research findings are applicable elsewhere or in other contexts (Lincoln & Guba, 1985). The main method of ensuring transferability is by providing a thick description of the phenomenon under investigation (Lincoln & Guba, 1985). Providing a detailed, rich description, rather than a superficial one, makes it easier to see whether or not and the extent to which the emergent concepts may be fit well in other settings (Lincoln & Guba, 1985). Transferability was increased in this study by doing exactly this; the aims of the analysis were to discover common experiences as well as the differences amongst participants, while also offering rich descriptions of individual and common experiences.

Dependability refers to the extent to which the research is repeatable (Lincoln & Guba, 1985). Being consistent in the methods of data collection and analysis are at the pinnacle of ensuring dependability (Lincoln & Guba, 1985). Here, and in the case of the present study, the analyst creates an audit trail, chronicling in detail the ways in which the data were analyzed, so that, if another researcher wishes to repeat the research, it will be possible (Lincoln & Guba, 1985).

The final component of trustworthiness proposed by Lincoln and Guba (1985) is that of confirmability, or neutrality: the extent to which the results were shaped by the participants' experiences and accounts rather than by researcher bias or interest. Acknowledging one's own background and preconceived notions – that is, being reflexive – is an important method of

ensuring confirmability (Lincoln & Guba, 1985). While a theoretical framework guided the creation of the data collection instrument and the analyses that ensued, it had the most impact at the level of structural themes and sub-themes. The content codes emerged independently of this guiding framework.

## **CHAPTER 4: RESULTS**

Six caregivers of people with dementia within the city of Ottawa, Ontario were participated in the study (Table 3). Of these, there were four women and two men, all identifying as Canadian and living in the city rather than rurally, with an average age of 68.8 years, ranging between 46 and 80 years. The average age for spouses was 73.4, and one daughter was aged 46. The participants' loved ones had been diagnosed with dementia an average of 5.7 years earlier, ranging from 3 to 10 years, and the diagnoses received were vascular dementia in three cases, Alzheimer's disease in two, and mixed dementia in the last case. Five of the six individuals live with the person with dementia. The average Zarit Burden Interview score among the participants was of 35.3, ranging between 19 and 57, which indicates mild to moderate burden. The individuals interviewed had used, were thinking about using, or had never used respite care over the course of their time as caregivers. While these data are presented above as a way of describing the study population at a glance, they will be discussed in greater detail when participants' stories are presented individually.

The major sub-themes identified in the data and discussed below are as follow:

- 1) Caregivers' hopes for the person with dementia,
- 2) Caregivers' expectations for the person with dementia,
- 3) Caregivers' hopes for themselves,
- 4) Respite care users' expectations for themselves, and
- 5) Respite care non-users' expectations for themselves.

## **5.1 Caregivers' Hopes and Expectations for Respite Care**

The first structural themes identified in the data were caregivers' hopes and expectations for respite care in a general sense (Table 2). These two themes were embedded into the interview guide, which was based on Leung et al.'s (2009) theoretical model; for this reason, they are referred to as structural themes rather than emergent content themes (Guest, MacQueen & Namey, 2012). In order for a segment of text to be identified as a hope for respite care it had to pertain to elements within a respite experience that the individual deems most desirable. Here, caregivers' hopes are the things that they perceive as being ideal and the best possible outcome of the phenomenon that is the use – real or hypothetical – of respite care. Portions of text were identified as pertaining to caregivers' expectations for respite care when the participant alluded to elements of a respite experience that they would deem most likely to occur. Here, the participants were referring to outcomes that they perceived as more likely, but not necessarily ideal.

Caregivers' initial reaction to speak to their hopes and expectations for their loved ones reflects the selflessness that is inherent to the act of caregiving. While these are very important factors to consider when making the decision to use or not use a service, respite care is meant to be for the caregiver first, and thus, it was essential to explore what they may hope for and expect for themselves out of such a service, whether or not they had used one. Below is a discussion of caregivers' hopes and expectations both for their loved one and for themselves.

## **5.2 Caregivers' Hopes and Expectations for the Person with Dementia**

When asked about their hopes and expectations for respite care, all six participants

defaulted to a discussion of what they do or would hope for and expect for their loved one, whose care would be in the hands of the service providers. In most cases, several of the hopes and expectations overlapped; that is, several of the things caregivers hoped for were also expected. For ease of visualization, caregivers' hopes and expectations for the person with dementia are illustrated in Figure 5.

Things that caregivers both hoped for and expected pertained to physical activity, social activity and entertainment, proper nutrition, safety and security, and high quality care. The participants felt that these items, which they perceived as ideal or wished for, were also perceived as realistically achievable by the respite care providers in the city. These particular hopes and expectations were consistent across participants who had or had not used respite care, and those who had used different types of respite care. The elements of a respite care experience that were perceived as both probable and ideal by the study participants are represented in the intersecting portion of Figure 5.

Physical activity, whether it is seated aerobic and strength exercises or walking, was mentioned as being a priority, and something the participants would consider to be ideal in a respite experience. Similarly, access to adequate social activity and entertainment were also seen as being very important and desired. Most respondents reported hoping and expecting that their loved one would be able to "have fun" in a respite situation. Furthermore, caregivers both hoped and expected that the person with dementia would have access to proper nutrition and be both safe and secure while in respite care. The final element that was identified as both a hope and expectation was high quality care. None of the respondents perceived the service providers as being unable to provide the level of care that they would deem as not only appropriate but also essential.

*So that's my expectation of any of these programs: he is entertained, he is fed a healthy meal, they do chair exercises, and... it's what he needs. He needs to be around people, 'cause he's a very social man.*

These hopes and expectations were consistent amongst caregivers who had and had not used respite care. Some participants referred to these as “the basics”: the baseline features that a program had to possess in order for it to be not only desirable, but a viable respite care option.

Another set of divergent hopes and expectations pertained to the participants' intention of using respite care as an intermediary between living at home and transitioning to long-term care for their loved one.

*Yeah they—the CCAC are in fact doing a full interview, uh, on [date], so I'm just at that stage. So even though I could probably go to the respite now, because I've already contacted the two institutions, uh, I haven't done that. I'm gonna wait 'til the assessment, see... what they consider—what—something that I might not have noticed and that I, that I need to do for her, or that I need to arrange for her.*

*I: Mhm. To see what kinds of things you guys qualify for.*

*Yeah. And then—but I think that'll put me in the position—in fact, if we go from respite to actual placement, it should—I'll have a case worker, you know, and I'll have a file, and I won't have to go through this another time.*

Another participant noted,

*I see the respite as, um—whether it is overnight stays at the [respite service provider] or whether it's a day program, it's getting him used to being away from me. And it's also me getting used to not having him here 24 hours a day. He needs to start identifying with other people, accepting help from other people.*

Here, participants hoped that their loved one would become accustomed to being around different people and to being cared for by someone other than their family caregiver and they hoped that it would make the transition easier.

Certain elements were identified as hopes but not expectations; that is, certain elements of the respite care experience were deemed to be ideal but not realistically achievable. The caregivers interviewed expressed that they hoped that their loved one would be happy when in a respite situation. Their expectation, however, was that the person with dementia may be resistant to or unhappy with the use of respite care for any number of reasons. These divergent hopes and expectations were identified by both participants who had and had not used respite care. Most caregivers acknowledged that their loved one may indeed not be pleased with their decision to use respite care, or may resist or be uninterested in the idea of using respite care at first.

*My hope would be that my mom would go without any issues, um, enjoy herself and make use of the facility and be happy [emphasis] being there. My expectation... is that would not happen. Um, I think she would be flustered and upset. Potentially. I guess it would depend on what stage things are at as well.*

Similarly, another participant explained:

*If she needs, you know, if she gets to the point where she needs, uh, she can't bathe herself, or she gets stuff like that, then I would depend upon them to, to come in and do that. I don't know how well she would accept it, but that's another problem."*

The main difference, here, between caregivers who had and had not used any form of respite care was that the current service users appeared to be more able to move past their loved one's resistance. All three participants who had never used formal respite services had attempted to use a day program in the past, but were unable to, due to refusal on behalf of the person with dementia. In these cases, the caregivers did not attempt to move past this refusal. This could be due to their perceived level of need for help, as compared to the higher level of need reported by those caregivers who were using respite care.

Similarly, one caregiver hoped that her loved one would have access to a private bedroom or independence at bath time in the case of longer term respite. Her expectation, however, was that these hopes are unrealistic and cannot reasonably be met in all situations.

*So there was the bath where someone would bathe him, and help him get in and out of the tub, and so on, and I thought, "oh, he's gonna hate this!" [laughs]. So I asked about a shower. Well, they've got a shower room as well, so they showed me that, and told me that they would do this much, and then he could go in, and that the... [...] the helper would stay outside the curtain and he could bathe himself and then they'd have to get the towel to him and so on after. So he'll feel very embarrassed, being seen by someone else. So a hope would be that he could do it without anyone seeing him. But I know that that's not likely to be the way it works. At the [name of respite service provider] he was able to do it independently. [...] But it looks as if that might not be the case if the one residence is an example of what they would do.*

*I: Mhm. So is something like that... would that make you hesitant to use such a service, knowing that?*

*No... No! [laughs] No. He might be annoyed with me. Very annoyed with me, quite upset. But... it's just the way it is.*

This participant was aware that the relative lack of privacy had the potential of upsetting her loved one and making him unhappy in a respite care experience. Privacy was mentioned by other respondents as being a hope, but not necessarily an expectation.

While these elements were seen as ideal and desired, the divergence between these hopes and expectations did not appear to deter caregivers from accessing services. The possibility of privacy and a loved one who is both happy and willing to use a service were identified as factors that would make utilizing respite care more appealing or ideal, but the absence of these do not appear to be major deterrents because, as mentioned above, that is "just the way it is" (Participant 3).

One element that was brought up by the three participants who utilized out-of-home respite services was the hope that there would be nursing staff on-site, both generally and with regards to a particular respite care centre in Ottawa. The expectation, here, was that there would not be nursing staff on-site because, as experience and word of mouth dictated, there was not. This was particularly problematic, as the lack of nursing staff had the potential to make certain individuals with dementia – those with physical health needs deemed too demanding by the facility – ineligible for participation in the particular respite program. Being diagnosed with a form of dementia does not preclude an individual from experiencing one or several physical comorbidities. The fact that a centre designed to host individuals with dementia, most of whom are of advanced age, was not equipped to cope with advanced physical health needs was perceived as very problematic by those caregivers who discussed it.

*We've used the [name of respite service provider]. And... we're not going to be able to use it again, apparently. [...] So that's frustrating, so anyway- no nursing staff is, I think, the basic problem there. The facility was lovely, it was a beautiful little spot, so uh, and the staff was very nice, but no, we were told that we couldn't use the facility again.*

*[later] Yeah, I guess my main thing and the frustration with the [respite provider] – what it could be, and what they've intended it to be, and what it's not.*

In the case of the above participant, the lack of nursing staff meant she could not access a specific service that she identified as having the potential to be an excellent resource. Those participants who had not used formal respite care did not broach the topic of the presence of nursing staff as either hopes or expectations, presumably because they had been unaware of the issue or its potential impact.

With the exception of the lack of nursing staff, each of these hopes and expectations were consistent among participants who had and had not used respite care, and among those who had used different types of services – whether it was a day program, longer term respite, or in-home respite.

### **5.3 Caregivers' Hopes and Expectations for Themselves**

The discussion of caregivers' hopes and expectations for themselves was different than the one above. First, their expectations varied depending on whether or not they had used a respite service, and depending on the type of service being used or discussed. The contrast was particularly evident when discussing day programs versus multi-day or night respite services.

#### **5.3.1 Respite Care Non-Users' Hopes and Expectations for Respite Care**

Among caregivers who had never used respite care, there was a distinct divergence between the elements of a hypothetical respite experience, which were both hoped for and expected. These hopes and expectations are presented in Figure 6. In the discussions with these participants, at no point was there a differentiation between what they hoped for and expected, nor was the sentiment that their hopes were unrealistic or unlikely to occur ever expressed.

These participants reported that they both hoped and expected to have a break, be able to have fun and do things for themselves, and socialize or do physical activity.

*I'll probably stay at home, just you know, do a little more canoeing and walking or biking or something like that, that I'm doing now.*

Another participant echoes this sentiment:

*I guess I would hope that I could have some... some time to do things that I might need to do. Some break, downtime. Um, time to rest, time to take care of other things that need to be taken care of.*

This aspect of the conversation was very brief when speaking to caregivers who had not used respite care. Their primary focus was on the person with dementia rather than themselves as the service consumer. These participants did not appear to perceive their hopes as being unrealistic or as having a low probability of occurring; rather, their hopes were also expected. This is in stark contrast to the hopes and expectations described by respite care users, which are described below.

### **5.3.2 Respite Care Users' Hopes and Expectations for Themselves**

The major difference between caregivers who were currently using respite care and those who had never accessed such a service in the past was the fact that the elements they hoped for were not always expected. In other words, the divergence between their hopes and expectations was more pronounced. The elements discussed below are presented in Figure 7. Current respite care users echoed the hopes identified by those caregivers who had never used respite. Again, the caregivers sampled hoped that they would be able to experience a pause in all caregiving activities, have the time to do things for themselves and have fun, and have the time to exercise and socialize, ultimately resulting in a reduction in caregiver burden.

*Um, just having—having a break away, not having to look at house work, just getting away a little bit. Not seeing the concerns of how much—how far behind I am [laughing] in everything. Yeah, just knowing that he's being looked after, well cared for, and uh, that he's happy.*

In a general sense, caregivers who were currently using respite care appeared to be satisfied by the amount of rest they get, and the extent to which it is a break. However, when probed about their hopes for themselves, a different story emerges, as it did in the case of a participant below.

*For me, it's a great rest. It's a way where I can get ready at the same time as him. It also makes it so that we can be out of the house before 11 o'clock in the morning. Now we can be out of the house by 10 or 9:30 if we absolutely have to. [...] So for me, it's a rest, it gives me—I can get myself ready, I can eat breakfast at breakfast time rather than at lunchtime.*

The above excerpt demonstrates the fact that this individual believes that respite care is affording her the ability to do the things she hopes for. Here, the participant cites being able to eat breakfast at a regular time and being able to get ready at the same time as her husband in the morning. By many standards, these might be considered basic elements of daily life that an individual does not consciously *hope* to be able to do in his or her daily life. When further probed about hopes for herself later in the interview, the discussion changed:

*I want to do some travelling. I want to spend more time with my family. I want to reconnect with my friends who have scattered all over the place. I want to be able to have a glass of wine when I want to have a glass of wine, rather than “ok, what am I doing, can I—do I have to do anymore driving tonight?” [laughs] Anything like that. I want—I want to have a lot of me time. I want to go to the spa and have a pedicure [laughs].*

The dialogue and tone change completely when the participant considered the perceived usefulness of respite care in comparison to things she really wished for in her personal life. This points, once again, to the selflessness of caregivers. Arguably, a pedicure and a glass of wine may not seem as essential to one's daily life as the ability to have a meal at a reasonable

hour; these types of experiences, though, may be what are missing for caregivers who are using day programs only or for those who have limited access to longer term respite options, for example.

A similar sentiment was shared by a participant who was taking the steps necessary to access longer term respite options. This participant was satisfied by the extent to which her current respite routine provided her with a break.

*I have used [in-home respite] to go away, uh, go for luncheon dates, uh, it works out well for that. I use it to go pay bills. The Wednesday, I often use to catch up a lot with things. But I do go out as well. I don't go for a whole day type of thing, but I do more socialization—well I, there's—the first Wednesday of the month, I go out in the afternoons.*

When the discussion became more future-oriented, the participant realized that the respite services currently being used might not give her the ability to do all of the things she deems not only desirable but also necessary.

*This is looking ahead, uh, in '17, June of '17 is my nursing reunion, and I want to go to that. Provided my health is there. And [PWD] will have to be taken care of. And that's one of the things I have in my mind, that he will be taken care of during that time, whatever aspect it takes at that time.*

The acknowledgment that an individual's current routine was not sufficient for the present time or for the future was a common one. For example, those caregivers who were using day programs only did not perceive themselves as being able to meet all of the hopes they had for themselves and, as such, began seeking out more comprehensive respite options.

Among caregivers who were using day programs, there was an expectation that they would not experience a great sense of relief from their caregiving duties. For many, day programs meant having just enough time to do housework, plan for the future (e.g. for long-term care, for future respite stays, etc.), and perhaps do some light leisure activities. However, it was not felt that day programs as a sole source of respite were enough for caregivers to meet their hopes for themselves. For this reason, two of the three out-of-home respite care users were seeking out longer term respite for themselves, aiming to begin gradually using them in the near future.

#### **5.4 Participant Stories**

While the results presented above offer an overview of the sample of individuals who participated in the study, an important objective of the study is to consider individual participants' stories in greater depth. These stories provide important context and nuance to the results, since the participants' lived experiences are rather different even though, demographically and generally speaking, they may seem similar. This section will shed light on some important constructs that may have only been brought up by one individual, but which still merit some attention and discussion. It is worth mentioning that the longer, denser interviews will involve a longer vignette, as compared to those interviews which were shorter.

*Participant 1.* This individual is the wife of a person with dementia, who was diagnosed with early-onset Alzheimer's disease six years ago. She reports that her husband requires care 24 hours a day, whether this care is provided by herself or someone else. Something that sets this individual apart from the others interviewed is the fact that she perceives that she has very

minimal social support available to her: the family members and friends with whom she is close all live in different provinces or parts of the world.

Over the past six years, P01 has accessed a variety of services: she has used day programs, longer term respite based in retirement homes and a designated respite care facility, and has recently been approved for weekly hours of in-home assistance for household tasks. At the time of the interview, she was utilizing day programs three days per week, and longer term respite care for several weeks of the year – approaching the maximum of ninety days per year allotted by the Community Care Access Centre. Participant 1 received a score of 57 on the Zarit Burden Interview, classifying her as having moderate to severe caregiver burden.

One problem reported by this participant but not others was the difficulty associated with having enough emergency contacts to remain eligible to use particular respite care centre. Between her own family and friends being scattered across the world and her step-children being generally unwilling to help, she has difficulty making use of the one service – longer term respite care – which helps her the most. While Participant 1 is the only individual in this study to have brought up the issue of emergency contacts and lack of family or social supports, it was a major barrier in her ability to access a respite service that she knew she felt that she could rely on.

The conversation with this participant shed light on the fact that burden may not be reducible by respite care. In fact, respite care may not even temporarily alleviate it, unless there is a complete detachment from the caregiving situation. P01, who found herself immersed in caregiving activities for several years, noted that while respite care may have

given her hope in the past, it did not currently; rather, the knowledge that long-term care will eventually be an option was what kept her going.

*While he's still in the house here, I can't do much for myself, and um—but since I have put his name on the list for long term care, that has created a light at the end of this very dark tunnel I've been in. And it's given me hope that there is an end to this. Which, unfortunately, it means an end to the person I married. But he's no longer the person I married.*

Throughout the interview, this individual alluded to her perception that respite care would not allow her to live the life she hoped for, to meet the hopes she had for herself; only her eventual perceived independence from her husband would afford her that possibility. Having been unable to meet her hopes and expectations through respite care, this participant has reformulated hopes and expectations for another service: long-term care.

*Participant 2.* This individual is also the wife of a person with dementia, who was diagnosed with vascular dementia seven years ago. This participant balances a reduced schedule at work with the care of her loved one, which involves extensive attention to physical health needs and surveillance of various medication doses. She uses a day program one day per week, and has attempted to use longer term respite at a specialized facility in the past. Unfortunately, this participant was told that the facility would be unable to host her husband in the future due to his more advanced physical health needs. This participant showed mild to moderate burden on the Zarit Burden Interview; in fact, she was on the cusp of a score indicating moderate to severe burden. At the time of the interview, this participant was exploring different longer term respite options at retirement homes and long-term care homes, because day program was not giving her the time off she felt she needed. Day programs allowed this participant the time to do one or two things she may need to do regardless of whether her loved on was in respite care; rather than spending time on meaningful activities

for herself, she found herself taking care of errands. This individual's account of her experience with day programs in particular appears to mirror those of the other day program users interviewed.

Participant 2 had a unique story in that she and her husband were unable to access respite care at the primary respite center in the city due to his physical health needs. This facet of her experience was described in greater detail above, since other participants brought up the problematic nature of the lack of nursing staff as well. With that said, this participant experienced more difficulty in accessing the longer term respite care she felt she desperately needed in order to achieve her hopes for herself and to maintain her role as caregiver.

Another element of P02's story that was particularly different was the fact that she perceived her loved one as being unable to understand her need to take a break, to use respite care. This is a factor that sets this participant apart from others, which may make her experiences with accessing respite care particularly difficult. While this lack of understanding on behalf of her husband is difficult and makes things more complicated, she is willing to take the steps necessary to access the services she needs. While this participant did not perceive that her hopes for herself were currently realizable, she did believe that utilizing further respite services might be able to help her achieve them. In other words, having determined that using day programs would not allow her to meet her hopes and expectations, she applied them to longer term respite services instead.

*Participant 3.* The wife of a person with dementia, Participant 3 was told that her husband had either developed dementia with Lewy bodies or vascular dementia. This individual is extremely well connected within her community through her involvement in her

church and volunteering activities, and has a good relationship with her children, who visit when they can. P03 appeared to be surrounded by helpful and supportive individuals who helped her to maintain the activities she valued most, such as attending board meetings for the organization in which she was involved. This participant accessed a day program on a weekly basis, as well as in-home respite care, and was working towards using longer term respite care. This individual was also considered mild to moderately burdened according to her Zarit burden score.

This individual, despite being responsible for extensive caregiving activities, both with regards to cognitive and physical health, appeared to remain actively involved in the activities she valued. The difference, here, was her perception that it would become more difficult to keep these commitments, coupled with her knowledge that losing the capacity to build these activities in her schedule would reduce her quality of life significantly. This was something she realized when her husband was physically ill and required more care than she had previously been providing. :

*One of the things that hit me when [PWD] was sick in December – and at that time it was 24 hour care that he was getting – uh, was that all of a sudden, all my freedom was gone. That I couldn't go out of the house unless somebody was here. And that sort of scared me. That was not something that I appreciated.*

Realizing that her role as a caregiver could expand or become too much at any time, P03 appeared to put measures in place so that she could continue to have time to herself, and so that her husband would be “used to” being away from her and receiving care from someone else. The ways in which this participant described planning for the future seemed decidedly practical; at every juncture of the journey, she seemed to be looking ahead at what might come, and what she might do to mitigate those changes.

*Participant 4.* This individual is the spouse of a person with dementia, whose wife had been diagnosed with vascular dementia approximately ten years prior. This participant received some respite, in theory, in that a caregiver came into the home on a weekly basis; however, this was not a community-based service, and the participant typically remained involved in caregiving activities during that time. This particular participant was beginning to think about using respite care. His score on the burden interview indicated mild to moderate burden. This participant had not used day programs at the time of the interview. He had attempted to bring his wife to such a program, but when the time came to attend the program, she had refused.

In starting the process of accessing respite care, he mentions that he has heard other caregivers' stories in meetings held by the Alzheimer Society.

*From what I've seen in the round tables that we've done, there's some of them [caregivers] that, that really severely need [respite care]. And they're not supported by family, they're not supported by—they get no help, and they're actually— people think they're exaggerating. You know, things like, about the state of the person, um, and exaggerating how much time it takes. [...] Some of them I don't think are aware that they need it. And that's, that's help—this is where the Alzheimer's Society helped me too. And just being—sitting around the table and people obviously needing it, and starting looking back on myself, “oh I don't need it, I'm still going out, I'm going out for a couple of hours and she—I can leave her alone.” So—but now I'm getting to think, “well, yeah, but what if?” You know?*

For this particular individual, the notion that things will not always be manageable – and seeing this happen to other people – initiated the process of seeking out respite care at longer term centres. While he did not express feeling as though he was in immediate need for help, he was aware of the fact that a day was likely to come when he did need help, and he expressed wanting to be prepared for that.

*Participant 5.* This participant is an individual whose wife was diagnosed with dementia and aphasia. P05's perception of his situation was that he did not yet need respite care, because he was able to manage the tasks that were required of him. Another element, here, was that he believed his wife may become upset if he were to ask for help in the home. When asked about his hopes or expectations for respite care, he never directly discussed what he may hope for or expect for himself.

Here, the notion of requiring help did not apply to him as the caregiver; instead, he perceived respite care as being a service that would help his wife. Much like Participant 4, Participant 5 attempted to use a day program as he felt it would be beneficial to his wife, but she refused to attend. It would appear, then, that this participant does not perceive his needs as substantial enough to move past his wife's resistance. It is worth mentioning, however, that this individual and his wife received the diagnosis approximately four years prior, and that everything is "still pretty new" to them.

*Participant 6.* This individual's mother was diagnosed with Alzheimer's disease approximately four years ago at the time of the interview. What set this participant apart from the other four was that she is the daughter of an individual with dementia rather than a spouse. P06 works full-time and has children, in addition to being the primary caregiver to her mother. They currently do not live together, as her mother remains independent enough to live on her own. With that said, this participant recently facilitated her mother's move to Ottawa so that they could spend more time together and so that she could provide a level of care that would not be possible if they lived apart. Participant 6's level of burden was quantified as mild to moderate with a score of 36.

P06 had never used any form of respite care before, whether it be a day program or a longer term option. This participant echoed the experiences of the two caregivers before her, in that she acknowledged that she and her mother had attempted to use day programs in the past, but her mother did not feel comfortable, and she “wasn’t going to push her to do it.”

This participant’s role as a caregiver may not be taxing enough that she perceives respite care as useful or as a necessity, beyond providing opportunities for socialization for her mother. Interestingly, this participant and the one before her appear to think of respite care as a service for their loved one rather than for themselves.

## **CHAPTER 5: DISCUSSION**

The results presented above suggest that introducing the distinction between hopes and expectations to the literature may serve not only to clarify the discussion on this subject but may help to initiate an important shift in service delivery. Discussing hopes and expectations separately and determining whether or not they converge could serve to inform service providers of the changes or improvements that may be perceived as necessary by their consumer base. If an individual's hopes and expectations are one and the same with regards to a particular service or aspect of a service, this could perhaps signal that it need not change. Conversely, hopes and expectations that are not only incongruent but also very dissimilar may signal to service providers that there are elements of the service that need to be reassessed. Respite care providers could use these hopes and expectations to understand caregivers' priorities and needs, and to guide what changes, if any, need to take place.

The results of this study suggest that there were no major differences between caregivers who had and had not used respite care when discussing their hopes for the person with dementia. Instead, the major difference emerged when comparing caregivers' hopes and expectations for themselves. Those caregivers who were using various respite services experienced more divergence between hopes and expectations than did those caregivers who had not used respite care, depending on the type of service being discussed. The results suggest that day programs do not offer the type of respite that caregivers need.

## 6.1 Respite Care

The literature on respite care and its impacts is broad. Certain studies have examined caregivers' hopes and expectations for respite care and other dementia-related services – oftentimes indirectly – with mixed results (Jurgens et al., 2012; Lund et al., 2009; Neville & Byrne, 2007; Phillipson & Jones, 2011). In their study, Neville and Byrne (2007) set out to assess caregivers' expectations specifically with regards to respite care. Their findings were that caregivers expected, above all else, that their loved one would be well taken care of, have access to social activities, and be happy (Neville & Byrne, 2007). The present study and its results support these findings, while also adding dimension by examining both hopes and expectations, and by specifically distinguishing between caregivers' hopes and expectations for their loved on as well as for themselves.

Phillipson and Jones' (2011) study focused on the differences in expectations between caregivers who had not used residential respite care and those who had. They reported that caregivers who had not used respite care held negative expectations about what may occur if they did (Phillipson & Jones, 2011). More specifically, these negative expectations pertained to the level of care that would be provided to their loved one in a respite setting (Phillipson & Jones, 2011). The results described here do not indicate these types of negative perceptions or expectations amongst the caregivers who had never used respite care. The negative expectations which were identified across both caregivers who had and had not used respite care were not deemed to be a reason not to use respite care, nor did they call into question the level of care their loved one does or would receive. Furthermore, the present study identified negative expectations for the caregivers themselves as the service users, which Phillipson and Jones's (2011) study did not explore.

The literature on caregiving and its impacts posits that the predominant goal of respite care is to alleviate caregiver burden by relieving caregivers of their duties, if only temporarily (Gilmour, 2002). Indeed, respite care does appear to alleviate objective burden, as described by Pinquart and Sörensen (2003), in that the practical implications of caregiving are removed for a certain period of time, be it a few hours or a few days. With that said, the results of this study suggest that respite care may not have the same effect on caregivers' subjective burden, that is, the emotional and psychological response to the requirements of their role as caregivers and to the difficulties associated with it (Pinquart & Sörensen, 2003). These results suggest that temporary alleviation of the practical demands of caregiving does not necessarily have an enduring impact on caregiver burden once the individual's respite period comes to an end.

## **6.2 Theoretical Framework: Hopes and Expectations**

As evidenced in the results presented above, there were marked differences between those caregivers who had used formal respite care and those who had not. These differences appear to fit well within Leung et al.'s (2009) model. In the model (Figure 1), several factors moderate the extent to which an individual's hopes and expectations converge or diverge when appraising possible outcomes and assessing their likelihood of occurring (Leung et al., 2009). Optimistic bias, prior knowledge, temporal proximity and controllability provide depth to the analysis of these differences and are of particular importance to this discussion.

Optimistic bias is defined as the overestimation of the probability of experiencing a positive event versus the risk of experiencing a negative one (Leung et al., 2009). Caregivers who had never used respite care appeared to have a stronger optimistic bias when it came to

their hopes and expectations for themselves. These caregivers both hoped and expected that they would be able to use respite care and utilize the time it afforded them as they pleased. Conversely, caregivers who had already had experience with respite care knew that it was not always to be expected that they would be able to have a break and truly rest. Leung et al. (2009) note that “experiences that contradict optimistic bias often result in more realistic expectations,” which was sometimes the case among caregivers who had used respite care as compared to those who had not.

Indeed, an individual’s prior knowledge or past experiences play an important role in this (Leung et al., 2009). Each caregiver interviewed displayed knowledge of the services being offered to caregivers in the city, but not all had experience with these. In the case of caregivers who had not used respite care, they did not have any personal experiences with using such a service to draw on when assessing the probability of the possible outcomes. While a lack of experience – either negative or positive – does not guarantee that a positive outcome will occur, it may not negatively affect perceptions in the way a negative experience might. Those caregivers who used day programs knew that it may not be enough for them to realize their hopes for themselves, and applied that knowledge to the decision to use or begin the process of seeking out longer term respite or long-term care placement to increase the likelihood of meeting these hopes and preserving their well-being. Two of the caregivers who had not used day program or any form of respite care simply did not have the same frame of reference around which to make the assessment of the likelihood of their hopes being met, and appeared to be biased toward the positive end of the spectrum. The third caregiver who had not used respite care had begun planning and realizing that his hopes and expectations would not always be consistent, because he saw other caregivers in desperate need of help in a support group

setting. This points to the fact that experiential knowledge does appear to play a role in the formulation of and differentiation between hopes and expectations.

Similarly, temporal proximity, the individual's perception of whether an event is near or far in the future (Leung et al., 2009), also illuminated the differences between respite care users and non-users with regards to their hopes for themselves. In the case of the participants who had never used any form of community based, formal respite care, there was a perception that they were "just not there yet," (Participants 5 and 6) with regards to needing respite. Not only did they not feel they needed it at the time of the interview, but they did not identify a specific time in the future when they might. There appeared to be a perception that the issues being discussed held no real bearing on the present moment; these participants acknowledged and understood that their loved one's disease was very likely to progress as the years advance, and that they may be in more need at that point, but these notions seemingly remained in the distant future. As such, there was no sense of urgency for these participants, and they appeared to remain optimistic.

Conversely, when it came to the participants who had used or were using respite care, there appeared to be a sense of urgency; in other words, the outcomes that these individuals were assessing were either already occurring with some regularity, or were on the cusp of occurring. According to Leung et al. (2009), it is easier to perceive the differences between hopes and expectations, and the likelihood of their occurrence, when an event will be taking place in the near or very near future. Those caregivers who were already using respite care were more aware of the differences between their hopes and expectations for themselves and appeared to be more realistic in their appraisals of these, which could be due, in part, to the fact that they were facing these issues in real time.

Leung et al.'s (2009) model also includes the element of controllability, or the extent to which an individual perceives that they have some control over a situation and its outcomes. The caregivers who were experiencing some inconsistency between their hopes and expectations did not appear to believe that they had as much control over the situation as did the caregivers who had not been using respite care.

Another aspect of the *appraisal of possible outcomes* is the precipitating phenomenon, an incident that leads to the individual beginning the formulation of and differentiation between hopes and expectations in the first place, “engender[ing] more critical appraisals of probabilistic outcomes or expectations” (Leung et al., 2009). In the case of caregivers who have used respite care, it can be reasonably assumed that a particular incident incited the caregiver to seek out respite care. While this was not explicitly asked during the course of the interview, caregivers did report there being a point at which they realized they needed more support than they were currently receiving.

The caregivers who had not yet used formal respite care, then, may not yet have encountered a precipitating phenomenon. Instead, they were asked to speak hypothetically to their hopes and expectations, considering what they think the outcomes of such a scenario may be, without feeling the pressure of an event occurring in real-time and causing them to make a real-life decision.

This brings forth an interesting difference between respite care users and non-users: those not using it do not feel that they need it, and those using it feel that they desperately need it, or need more than the services they are able to access. This may suggest that, at some point over the course of the caregiving journey, a threshold is reached, at which point the caregiver

is no longer able to manage in the ways that they had in the past. Suddenly, they are unable to cope with the “all-encompassing” (Participant 1) nature of their role as caregiver, or with the near-impossibility of engaging in activities that are meaningful to themselves and that are not being done for anyone other than themselves. Chatillon et al. (2012) discussed the association between activity restriction and decreased caregiver health; perhaps, then, this restriction also plays a role in the burden experienced by the individual. This points to the importance of focussing on the caregiver rather than only the person with dementia when discussing respite care and its effectiveness. In effect, the caregiver should be viewed as the care recipient of respite care.

Identifying the point in time at which caregivers find the subjective burden of placing another individual’s wellbeing ahead of their own because too much may be a crucial aspect in ensuring that respite care provides caregivers with what they need. A different perspective may be an exploration of the point at which caregivers perceive themselves as being unable to deal with relinquishing the hopes they have for themselves in favour of focussing their energy on their loved one. It would appear that, at a certain point, this is not feasible and cannot continue indefinitely. What remains unclear, however, is what causes this – the unbearable, sudden onset of severe burden – and whether or how it may be generalized across individuals.

## **CHAPTER 7: LIMITATIONS**

The main limitation of this study is the participants recruited. First, the sample is not as varied as initially hoped for when participant recruitment began; purely non-probabilistic sampling was intended, but convenience sampling was eventually deemed more feasible, keeping in mind the importance of variability. Being able to recruit a caregiver who was the son of a person with dementia as well as caregivers living in more rural areas would have added richness to the data collected. Second, the sample is decidedly small. Due to time constraints, it was not within the scope of this study to continue recruitment in order to expand the sample size. Despite the small sample, thematic saturation was reached in the general themes raised by participants. It is of course impossible to generalize these six participants' experiences to a broader population; indeed, this was not one of the study's aims. Instead, this data offers a glimpse into individual experiences, providing some indication of the potential application the theoretical framework of hopes and expectations to the examination of service use.

Another limitation pertaining to the sample is that each participant interviewed had some connection to the Alzheimer Society of Ottawa and Renfrew County. In other words, the participants were connected to a supportive and educational network in some way, and it would be irresponsible to assume that this is a reality for all caregivers. The data may have been very different if the sample represented some individuals who were not part of such a network. Due to the difficulties encountered during recruitment and the time constraints imposed by the study, it was impossible to expand recruitment further.

Finally, the author acknowledges that these data represent a moment in time. Caregiving is not static, and it is entirely possible that the results of this study were influenced by a variety of factors in the individuals' lives.

## **CHAPTER 8: CONCLUSIONS & FUTURE DIRECTIONS**

The present study demonstrates that caregivers reported varied hopes and expectations, both for their loved ones and for themselves, when using or considering using respite care. For the most part, caregivers' hopes and expectations for their loved one converged. Conversely, caregivers' hopes and expectations for themselves tended to converge or diverge depending on whether or not they had used respite care in the past. Beyond this, these differences appeared to be well explained by Leung et al.'s (2009) theoretical framework.

While these hopes and expectations, whether they converged or diverged, did not appear to play an explicit role in the decision to use or not use respite care, they may be important factors to integrate into discussions of existing services and may enhance the dialogue between service consumers and providers. Respite care is, after all, a service designed to help the caregiver, and exploring these hopes and expectations may reveal ways in which caregivers can gain more from respite care when they use it. Examining day programs – a very widespread respite option – more specifically would be an interesting avenue of future research. The results presented above suggest that day programs offer caregivers the opportunity to continue caregiving more than they offer the ability to take a break. More research is needed to further explore this finding.

This study's results would be strengthened by conducting a larger study with more participants and, eventually, assessing the outcomes of caregivers' hopes and expectations. Conducting longitudinal analyses to determine the ways in which these hopes and expectations change over time in response to a variety of factors would also be an interesting future direction to take.

Studies that re-frame the caregiver as the care recipient in a respite care situation, while aiming to better understand why respite care does not appear to alleviate burden beyond a certain point, would be an invaluable addition to the literature. Better understanding of exactly what is needed in order for caregivers to maintain their roles, rather than simply stating that they must be mindful of their own health, will be essential as the incidence of dementia continues to rise.

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## Tables

**Table 1.** Semi-structured interview guide

	<b>INTERVIEW QUESTIONS</b>
All participants	<ul style="list-style-type: none"> <li>-How old are you?</li> <li>-What cultural background do you identify with?</li> <li>-Would you say you live in the city or in a more rural area?</li> <li>-Do you work outside the home?</li> <li>-Are you and PWD related? What is your relationship? Do you live together or apart?</li> <li>-What type of dementia were you told PWD has?</li> <li>-How long ago were you told PWD had dementia?</li> <li>-Can you tell me a bit about your caregiving activities? What kinds of activities do you include in the care of PWD?</li> <li>-How many hours would you estimate you spend caregiving each week?</li> <li>-What kinds of social supports do you have available to you?</li> <li>-[Administration of the Zarit Burden Interview]</li> <li>-Have you ever used respite care?</li> </ul>
Caregivers who had never used respite care (did not want to, or were thinking about it)	<ul style="list-style-type: none"> <li>-What do you know about the respite services available in Ottawa?</li> <li>-Have you ever thought about using respite care?</li> <li>-What do you think would happen if you were to use a respite service?</li> <li>-Would you say that your expectations played a role in your decision not to use respite care?</li> <li>-What do you wish/hope would happen if you were to use a respite service?</li> <li>-What do you think others would wish/hope for out of respite care?</li> <li>-What would it take for your hopes to be met, for you to want to use or take the steps necessary to use respite care?</li> </ul>
Caregivers who were currently using respite care	<ul style="list-style-type: none"> <li>-Can you tell me about the service(s) you're using?</li> <li>-How frequently do you use respite care?</li> <li>-How long does each respite session last?</li> <li>-What do you think will/expect to happen when you use respite care?</li> <li>-To what extent would you say that your expectations are being met?</li> </ul>

	<ul style="list-style-type: none"><li>-Would you say that your expectations played a role in your decision to use respite care?</li><li>-What do you hope to get out of respite care when you use it?</li><li>-To what extent would you say that your hopes are being met?</li><li>-What do you think others would wish/hope for out of respite care?</li><li>-What would it take for your hopes to be met?</li><li>-Do you know about other services available in Ottawa, other than the one(s) you are using?</li></ul>
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**Table 2.** Applied Thematic Analysis codebook

Structural Themes	Structural Sub-Themes	Content Codes	Content Code Definitions
<p><b>Hopes for respite care</b></p> <p>The ideal outcome in a situation</p>	<p><b>Hopes for PWD</b></p> <p>The ideal outcome for PWD in a respite situation</p>	Physical activity-PWD	Hope that PWD would have access to physical activity e.g. chair fitness
		Entertainment/Social activity-PWD	Hope that PWD would have access to other individuals, be social
		Good care	Hopes that PWD would be well taken care of and well treated by staff
		Nursing staff	Hope that there would be nursing staff on site at residential respite care facility
		Safety, security	Hope that PWD would be both safe and secure in the respite environment
		Healthy meals	Hope that the facility would provide fresh, healthy food
		Facilitate move to LTC	Hope that PWD would get used to other people providing care
		Privacy	Hope that PWD could have some privacy during bath time, bed time
		PWD happy to attend	Hope that PWD would be excited to attend respite, not resist
	<p><b>Hopes for self</b></p> <p>The ideal outcome for self in a respite situation</p>	Stop caregiving	Hope that caregiver (CG) would be able to pause all care activities
Physical activity-CG		Hope that CG would be able to do exercise, alone or with others	

		Social activity-CG	Hope that CG would be able to spend time with friends and family
		Have a break, rest	Hope that CG would be able to rest, recharge
		Have fun	Hope that CG would be able to take part in pleasurable activities
<p><b>Expectations for respite care</b></p> <p>The most likely outcome in a situation</p>	<p><b>Expectations for PWD</b></p> <p>The most likely outcome for PWD in a respite situation</p>	Physical activity-PWD	Expectation that PWD would have access to physical activity e.g. chair fitness
		Entertainment/Social activity-PWD	Expectation that PWD would have access to other individuals, be social
		Good care	Expectation that PWD would be well taken care of and well treated by staff
		No nursing staff	Expectation that there would not be nursing staff on site at a certain residential respite care facility
		Safety, security	Expectation that PWD would be both safe and secure in the respite environment
		Healthy meals	Expectation that the facility would provide fresh, healthy food
		Facilitate move to LTC	Expectation that PWD would get used to other people providing care
		Less privacy	Expectation that PWD may not have as much privacy during bath time, bed time as they would at home

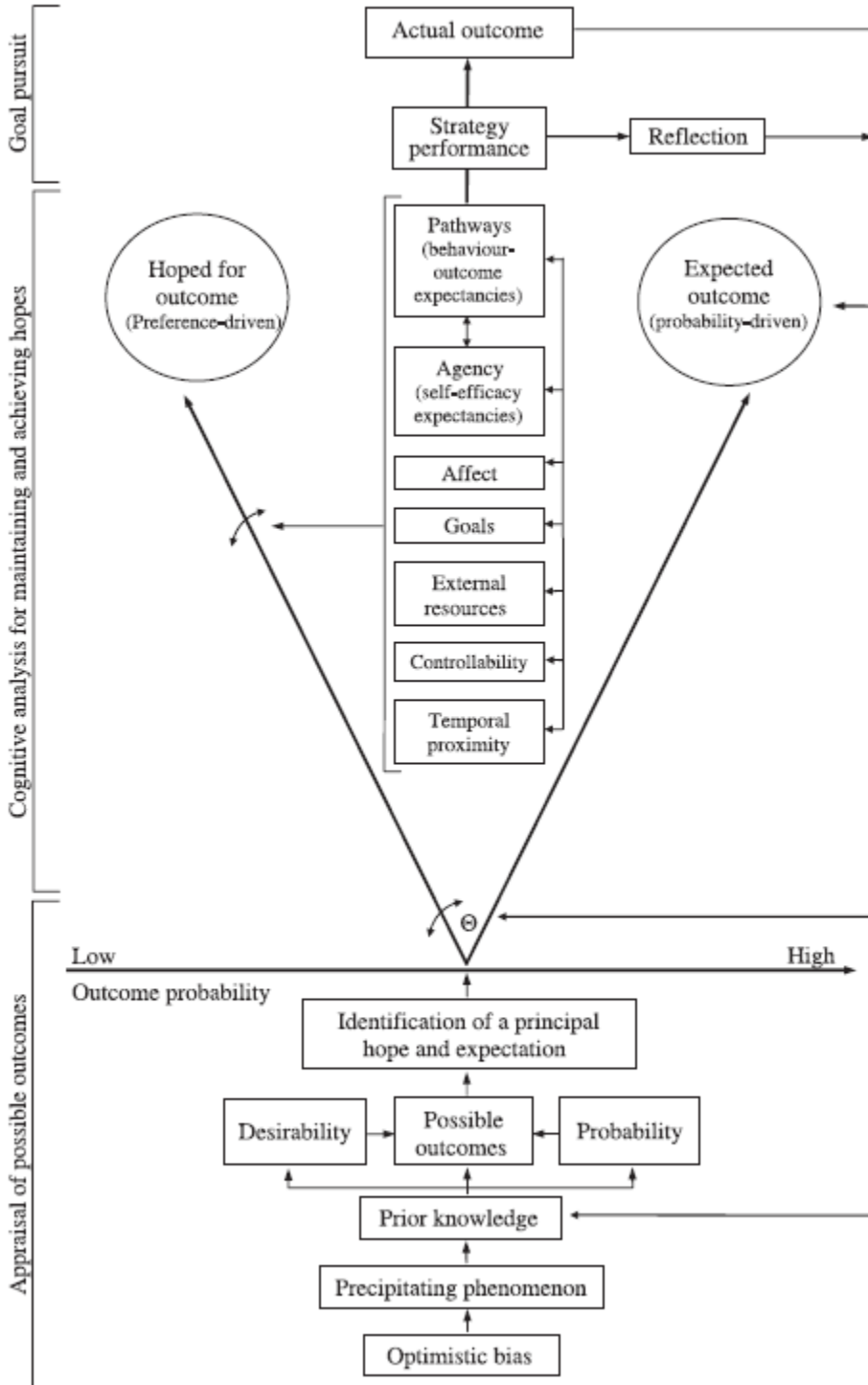
		PWD resistance	Expectation that PWD might display some resistance to attending respite care
	<p><b>Respite care users' expectations for self</b></p> <p>The most likely outcome for self in a respite situation, among service users</p>	Continue caregiving	Expectation that CG would continue engaging in indirect care activities
		Plan for the future	Expectation that CG would spend time planning for PWD's future
		Housework	Expectation that CG would spend time on household chores
		No break, rest	Expectation that CG would not experience much rest
	<p><b>Respite care non-users' expectations for self</b></p> <p>The most likely outcome for self in a respite situation, among service non-users</p>	Stop caregiving	Expectation that CG would be able to pause all care activities
		Physical activity-CG	Expectation that CG would be able to do exercise, alone or with others
		Social activity-CG	Expectation that CG would be able to spend time with friends and family
		Have a break, rest	Expectation that CG would be able to rest, recharge

**Table 3.** Demographic information

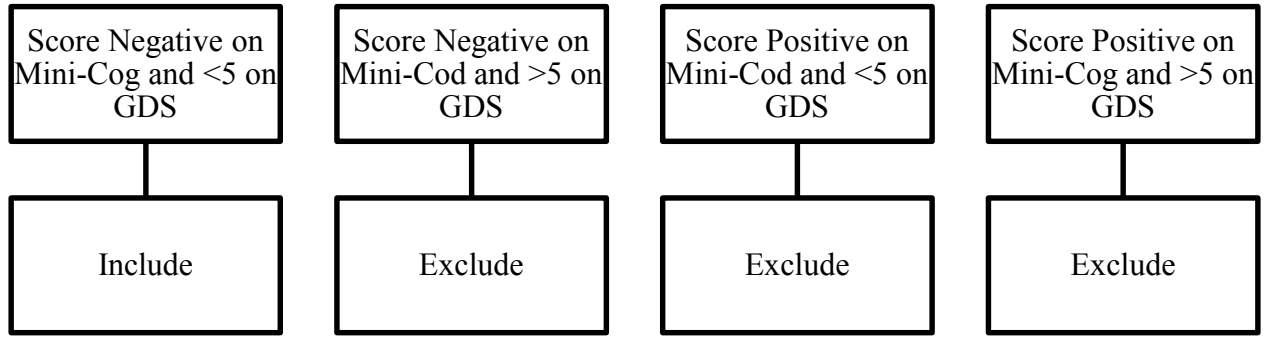
Sex	Male	2
	Female	4
Age (years)	Average	68.8
	Median	73
Relationship to PWD	Spouse	5
	Daughter	1
Type of dementia	Alzheimer's Disease	2
	Vascular	3
	Mixed	1
Years caregiving	Average	5.7
Employment status	Not employed	4
	Part-time	1
	Full-time	1
Zarit Burden score	Average	35.3
Respite care use	Yes	3
	No	3

## Figures

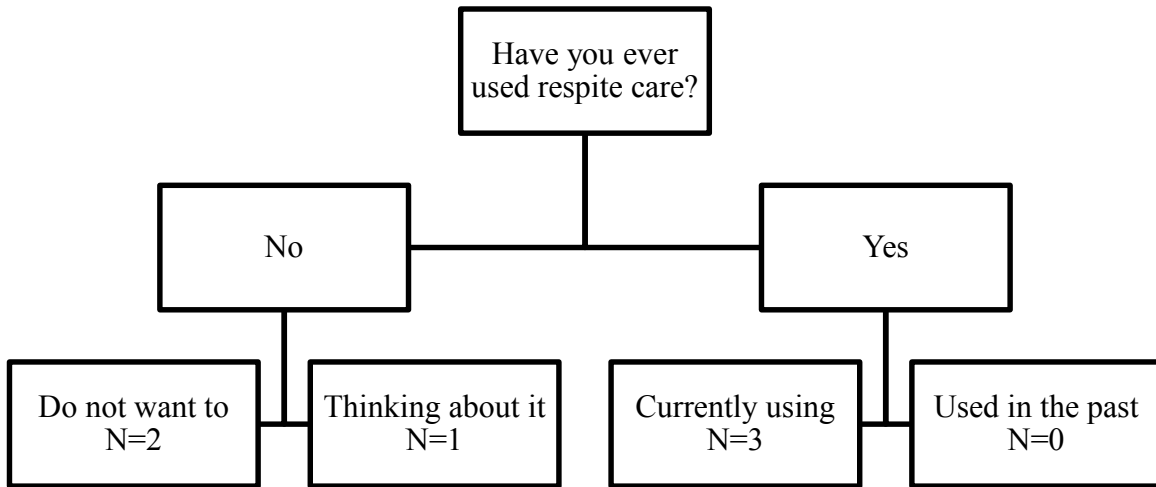
**Figure 1.** Model of hopes and expectations (Leung et al., 2009)



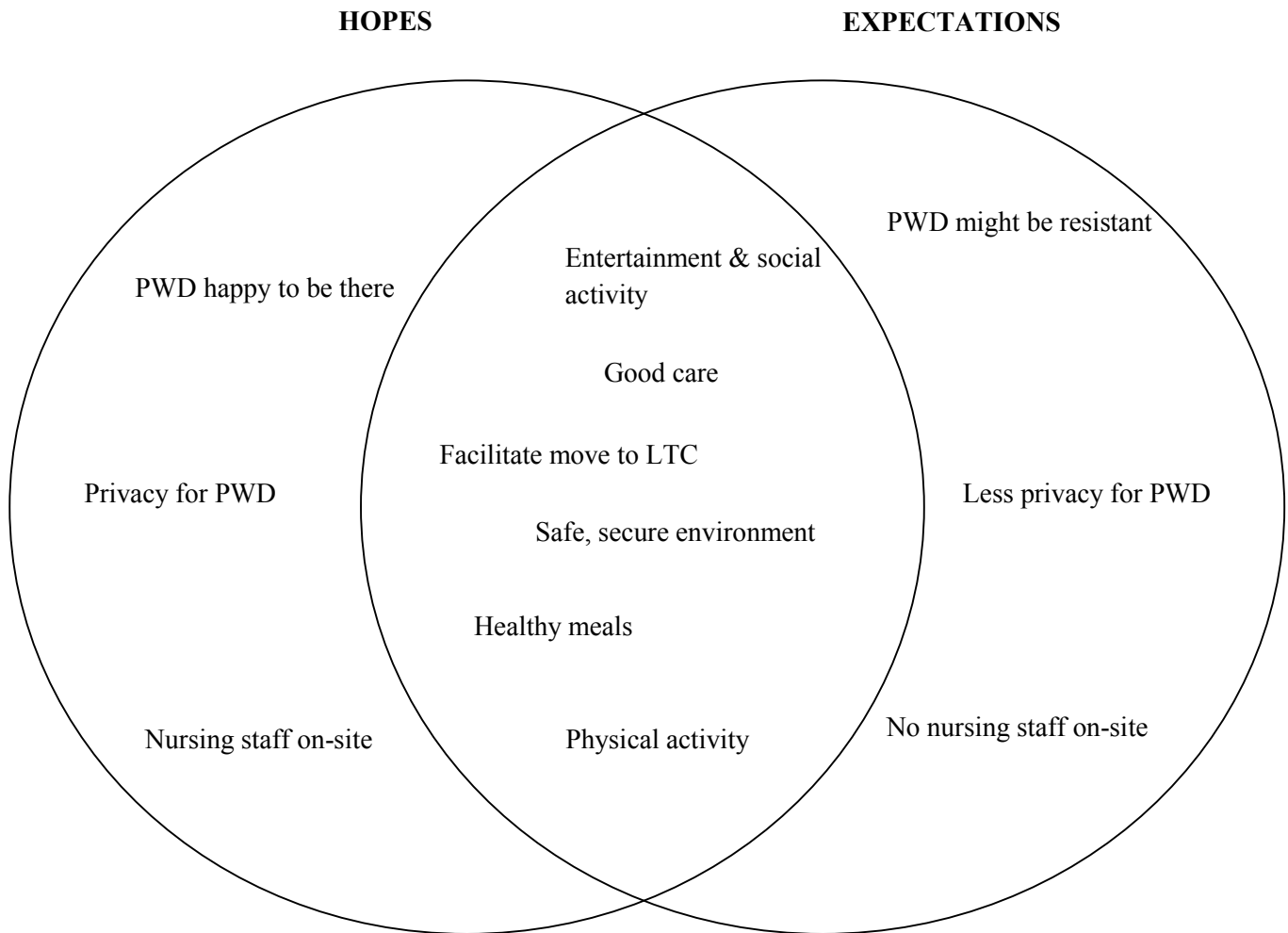
**Figure 2.** Inclusion or exclusion of participants based on Mini-Cog and Geriatric Depression Scale scores



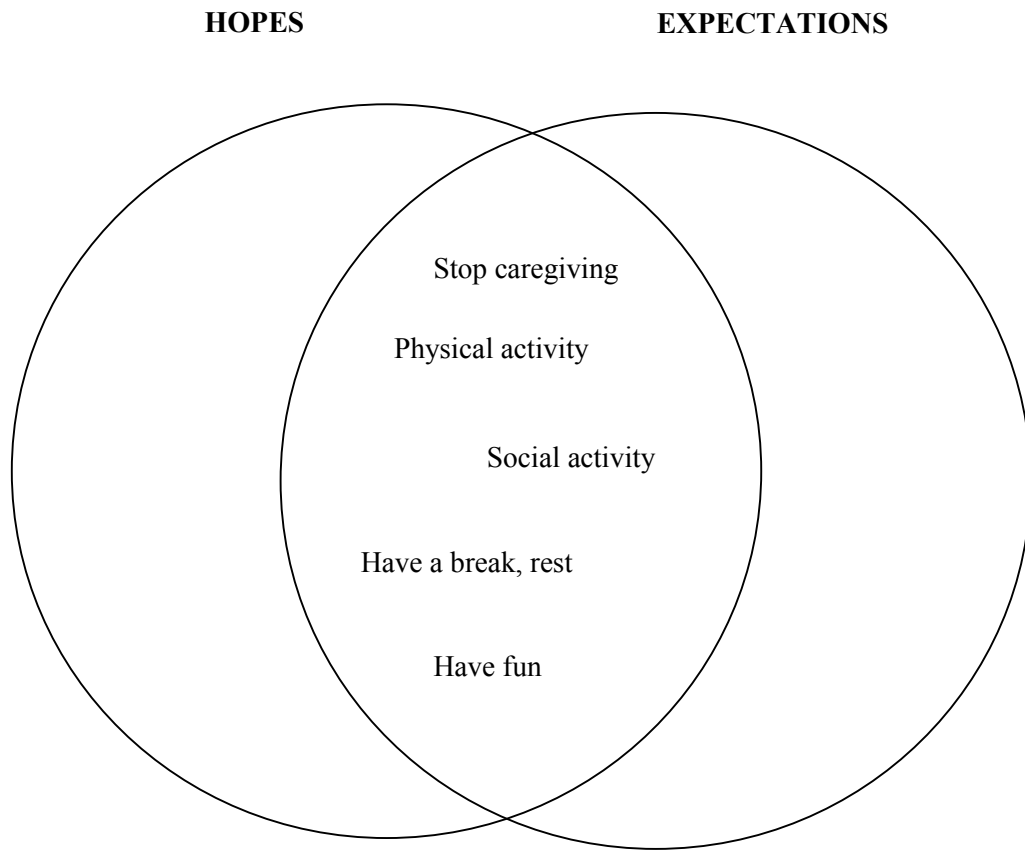
**Figure 3.** Categorization of included participants based on respite care use.



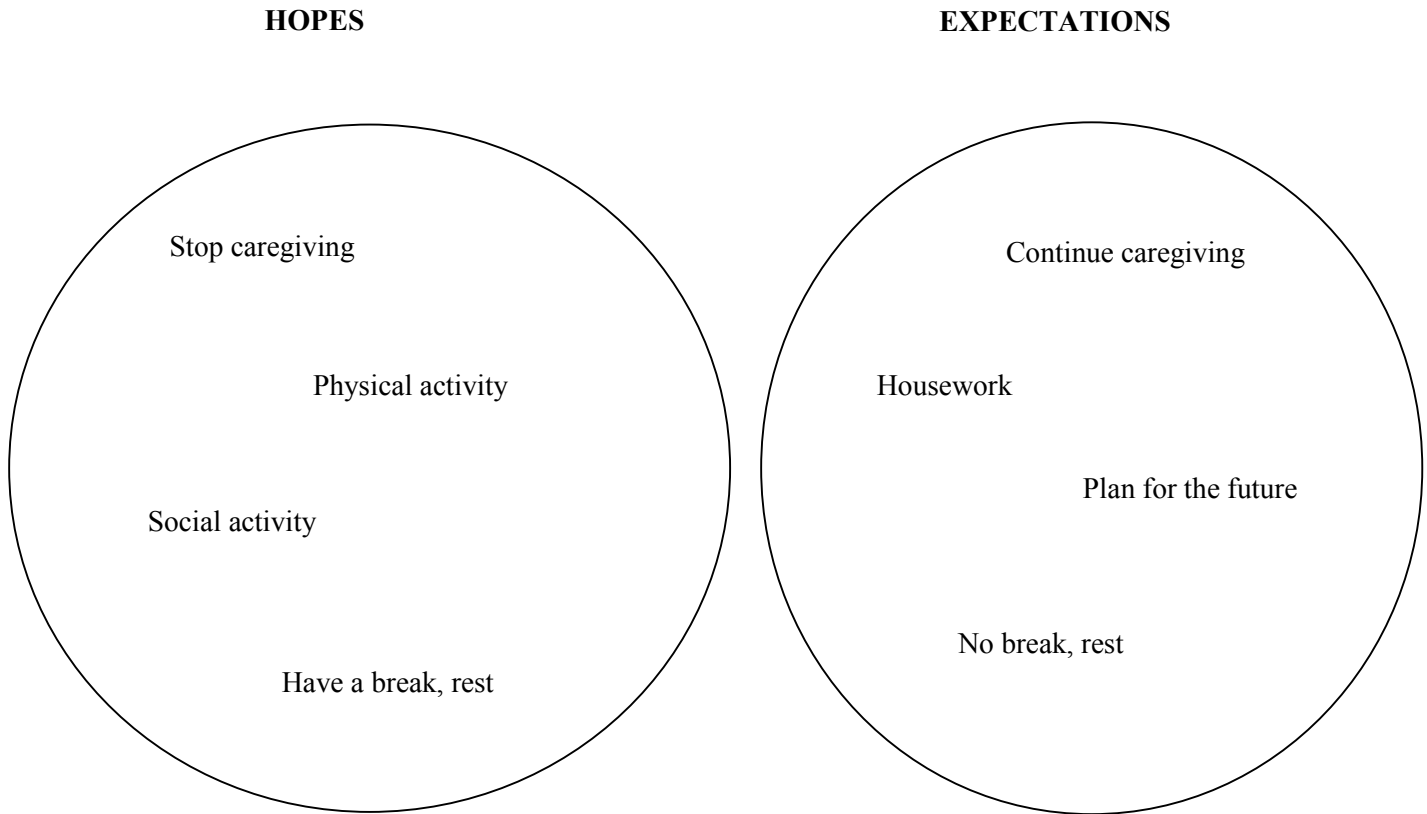
**Figure 4.** Caregivers' hopes and expectations for the person with dementia



**Figure 5.** Respite care non-users' hopes and expectations for themselves



**Figure 6.** Respite care users' hopes and expectations for themselves



## Appendices

**Appendix A:** Ethics approval and renewal from University of Ottawa REB

**File Number:** H03-14-11

**Date (mm/dd/yyyy):** 06/09/2014



**Université d'Ottawa**  
Bureau d'éthique et d'intégrité de la recherche

**University of Ottawa**  
Office of Research Ethics and Integrity

**Ethics Approval Notice**

**Health Sciences and Science REB**

**Principal Investigator / Supervisor / Co-investigator(s) / Student(s)**

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Linda J.	Garcia	Health Sciences / Others	Supervisor
Marie	Agapitos	Health Sciences / Others	Student Researcher

**File Number:** H03-14-11

**Type of Project:** Master's Thesis

**Title:** Assessing Caregivers' Hopes and Expectations for Respite Care

<b>Approval Date (mm/dd/yyyy)</b>	<b>Expiry Date (mm/dd/yyyy)</b>	<b>Approval Type</b>
06/09/2014	06/08/2015	Ia

(Ia: Approval, Ib: Approval for initial stage only)

**Special Conditions / Comments:**

N/A

File Number: H03-14-11

Date (mm/dd/yyyy): 06/09/2015



**Université d'Ottawa**  
Bureau d'éthique et d'intégrité de la recherche

**University of Ottawa**  
Office of Research Ethics and Integrity

## **Ethics Approval Notice**

### **Health Sciences and Science REB**

#### **Principal Investigator / Supervisor / Co-investigator(s) / Student(s)**

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Linda J.	Garcia	Health Sciences / Others	Supervisor
Marie	Agapitos	Health Sciences / Others	Student Researcher

**File Number:** H03-14-11

**Type of Project:** Master's Thesis

**Title:** *Assessing Caregivers' Hopes and Expectations for Respite Care*

<b>Renewal Date (mm/dd/yyyy)</b>	<b>Expiry Date (mm/dd/yyyy)</b>	<b>Approval Type</b>
06/09/2015	06/08/2016	Ia

(Ia: Approval, Ib: Approval for initial stage only)

**Special Conditions / Comments:**

N/A

**Appendix B.** Recruitment flyer

# Seeking Participants: Caregivers of people with dementia

We know that taking care of someone with dementia can be stressful.

*Do you ever take time off for yourself?*

*Have you ever considered using respite care?*



We are looking for caregivers to talk about hopes and expectations for respite care.

Questions or comments? Call or email Marie Agapitos at

[REDACTED] Ethics approval has been obtained from the University of Ottawa Research Ethics Board.

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## We want to hear from you!

If you wish to be contacted directly about this study, please fill out the information below. Participants will be selected on a first come, first served basis. Please print clearly.

Name: \_\_\_\_\_

Contact information (phone or email): \_\_\_\_\_

Check off the option that best applies to you:

- I've never used respite care, and I don't want to
- I've never used respite care, but I'm thinking about it
- I'm currently using respite care
- I have used respite care, but am not currently

**Appendix C. Geriatric Depression Scale: Short Form (Yesavage et al., 1983)**

## **Geriatric Depression Scale: Short Form**

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life? **YES** / NO
2. Have you dropped many of your activities and interests? **YES** / NO
3. Do you feel that your life is empty? **YES** / NO
4. Do you often get bored? **YES** / NO
5. Are you in good spirits most of the time? **YES** / NO
6. Are you afraid that something bad is going to happen to you? **YES** / NO
7. Do you feel happy most of the time? **YES** / NO
8. Do you often feel helpless? **YES** / NO
9. Do you prefer to stay at home, rather than going out and doing new things? **YES** / NO
10. Do you feel you have more problems with memory than most? **YES** / NO
11. Do you think it is wonderful to be alive now? **YES** / NO
12. Do you feel pretty worthless the way you are now? **YES** / NO
13. Do you feel full of energy? **YES** / NO
14. Do you feel that your situation is hopeless? **YES** / NO
15. Do you think that most people are better off than you are? **YES** / NO

Answers in **bold** indicate depression. Score 1 point for each bolded answer.

A score > 5 points is suggestive of depression.

A score ≥ 10 points is almost always indicative of depression.

A score > 5 points should warrant a follow-up comprehensive assessment.

**Appendix D. Mini-Cog (Borson et al., 2000)**

**MINI-COG™**

Instructions

ADMINISTRATION	SPECIAL INSTRUCTIONS						
<p>1. Get patient's attention and ask him or her to remember three unrelated words. Ask patient to repeat the words to ensure the learning was correct.</p>	<ul style="list-style-type: none"> <li>• Allow patient three tries, then go to next item.</li> <li>• The following word lists have been validated in a clinical study:<sup>1-3</sup></li> </ul> <table style="width: 100%; border: none;"> <tr> <td style="vertical-align: top;"> <p><b>Version 1</b></p> <ul style="list-style-type: none"> <li>• Banana</li> <li>• Sunrise</li> <li>• Chair</li> </ul> </td> <td style="vertical-align: top;"> <p><b>Version 3</b></p> <ul style="list-style-type: none"> <li>• Village</li> <li>• Kitchen</li> <li>• Baby</li> </ul> </td> <td style="vertical-align: top;"> <p><b>Version 5</b></p> <ul style="list-style-type: none"> <li>• Captain</li> <li>• Garden</li> <li>• Picture</li> </ul> </td> </tr> <tr> <td style="vertical-align: top;"> <p><b>Version 2</b></p> <ul style="list-style-type: none"> <li>• Daughter</li> <li>• Heaven</li> <li>• Mountain</li> </ul> </td> <td style="vertical-align: top;"> <p><b>Version 4</b></p> <ul style="list-style-type: none"> <li>• River</li> <li>• Nation</li> <li>• Finger</li> </ul> </td> <td style="vertical-align: top;"> <p><b>Version 6</b></p> <ul style="list-style-type: none"> <li>• Leader</li> <li>• Season</li> <li>• Table</li> </ul> </td> </tr> </table>	<p><b>Version 1</b></p> <ul style="list-style-type: none"> <li>• Banana</li> <li>• Sunrise</li> <li>• Chair</li> </ul>	<p><b>Version 3</b></p> <ul style="list-style-type: none"> <li>• Village</li> <li>• Kitchen</li> <li>• Baby</li> </ul>	<p><b>Version 5</b></p> <ul style="list-style-type: none"> <li>• Captain</li> <li>• Garden</li> <li>• Picture</li> </ul>	<p><b>Version 2</b></p> <ul style="list-style-type: none"> <li>• Daughter</li> <li>• Heaven</li> <li>• Mountain</li> </ul>	<p><b>Version 4</b></p> <ul style="list-style-type: none"> <li>• River</li> <li>• Nation</li> <li>• Finger</li> </ul>	<p><b>Version 6</b></p> <ul style="list-style-type: none"> <li>• Leader</li> <li>• Season</li> <li>• Table</li> </ul>
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<p>2. Ask patient to draw the face of a clock. After numbers are on the face, ask patient to draw hands to read 10 minutes after 11:00 (or 20 minutes after 8:00).</p>	<ul style="list-style-type: none"> <li>• Either a blank piece of paper or a preprinted circle (other side) may be used.</li> <li>• A correct response is all numbers placed in approximately the correct positions AND the hands pointing to the 11 and 2 (or the 4 and 8).</li> <li>• These two specific times are more sensitive than others.</li> <li>• A clock should not be visible to the patient during this task.</li> <li>• Refusal to draw a clock is scored abnormal.</li> <li>• Move to next step if clock not complete within three minutes.</li> </ul>						
<p>3. Ask the patient to recall the three words from Step 1.</p>	<p>Ask the patient to recall the three words you stated in Step 1.</p>						

Scoring

<p><b>3 recalled words</b></p> <p><b>1-2 recalled words + normal CDT</b></p> <p><b>1-2 recalled words + abnormal CDT</b></p> <p><b>0 recalled words</b></p>	<p>Negative for cognitive impairment</p> <p>Negative for cognitive impairment</p> <p>Positive for cognitive impairment</p> <p>Positive for cognitive impairment</p>
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## Appendix E. Letters to family physicians



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### Appendix E: Letter to Family Physician – Geriatric Depression Scale (Yesavage, J. et al., 1983).

**Research Project Title:** Assessing caregivers' hopes and expectations for respite care

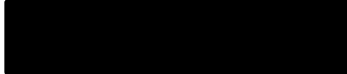
**Primary Investigator;**

Marie Agapitos



**Thesis Supervisor;**

Linda Garcia



To whom it may concern:

I, \_\_\_\_\_, scored higher than 5 on the Geriatric Depression Scale. The researchers have informed me that this could be indicative of depression. For this reason, I was ineligible to participate in Marie Agapitos' study on the hopes and expectations of caregivers of people with dementia.

It was recommended that I give this letter and a blank copy of the testing instrument to you, my family physician, in order to discuss what this score means.

Thank you.



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**Appendix D: Letter to Family Physician – Mini-Cog Test  
(Borson et al., 2000).**

**Research Project Title:** Assessing caregivers' hopes and expectations for respite care

**Primary Investigator;**

Marie Agapitos



**Thesis Supervisor;**

Linda Garcia



To whom it may concern:

I, \_\_\_\_\_, scored positive on the Mini-Cog test (non-numeric scoring only). The researchers have informed me that this could be indicative of cognitive decline. For this reason, I was ineligible to participate in Marie Agapitos' study on the hopes and expectations of caregivers of people with dementia.

It was recommended that I give this letter and a blank copy of the testing instrument to you, my family physician, in order to discuss what this score means.

Thank you.

**Appendix F. Zarit Burden Interview (Zarit, Reeve, Back-Peterson, 1980)**

**THE ZARIT BURDEN INTERVIEW**

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
<b>Total Score (out of 88)</b>						

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Interpretation of Score:	
0 – 21	little or no burden
21 – 40	mild to moderate burden
41 – 60	moderate to severe burden
61 – 88	severe burden

Score values and interpretation are guidelines only, as discussed in:  
 Hebert R, Bravo G, and Preville M (2000). *Canadian J Aging* 19: 494-507.

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