BARRIERS TO INSTITUTIONAL RESPITE FOR ALZHEIMER'S CAREGIVERS

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By

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Abstract

As the incidence of elderly-type illnesses such as Alzheimer's Disease continues to increase along with the elderly population in Canada, the particular health concerns and formal service needs of dementia patients and their caregivers are becoming more apparent and important to researchers, policy analysts, and ministry representatives. Institutional respite is one service that has been consistently underutilized by the Alzheimer's population, but little research has been conducted to determine the reasons behind why this is the case.

As part of its Alzheimer strategy, the Ontario Government has promised to invest $7 million annually into respite services for caregivers. It is essential that these monies be used as appropriately as possible and in ways that best assist caregivers, and one of the easiest ways to do this is to include caregiver input in the processes of service evaluation, modification, and development. This study focuses on uncovering the issues that contribute to Alzheimer's caregivers underutilization of institutional respite, with the hope that this paper and like papers in the future will contribute to the development of more generous and more appropriate respite services for families caring for persons with Alzheimer's Disease.

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Introduction

The Ontario Government currently offers ninety days of institutional respite at a reduced rate of $31.67. The majority of families caring for a loved one with AD qualify for this service, however, utilization rates for Alzheimer's caregivers remain extremely low. One concern is that policy makers and government ministers very narrowly assess the impact of institutional respite by how much it improves caregiver burden and delays permanent long-term placement (Flint, 1995; Montgomery, Marquis, Schaefer, & Kosloski, 2002). Another concern is that service evaluation is often done without adequate input from caregivers, and without considering the many methodological impediments to studying respite use with this particular population. It is hoped that this research will demonstrate the need for ministries to develop more appropriate ways of assessing respite usage and for legislation and policy to be more sensitive to the needs of Alzheimer's caregivers and to take direction from them in the development of future services.

One major methodological issue addressed here is that respite utilization studies have often grouped together day, in-home and institutional respite instead of recognizing that the barriers to use may be different across the three types. There appears to be a number of caregivers who willingly use day away programs or in-home services who do not use long-term respite in an institution, therefore, the main purpose of this study was to examine the barriers specific to institutional respite.

A qualitative study was undertaken to explore what caregivers and key professionals had to say about the reasons why institutional respite is rarely used by families caring for a loved one with Alzheimer's Disease. A sample of primary caregivers, a long-term care admissions social worker, and a CCAC case manager were interviewed to learn more about the process through which Alzheimer's caregivers arrive at their decision to seek or use institutional respite. The research also sought to uncover caregivers' and professionals' perceptions of the institutional respite system in general and to identify changes that would make services more accessible and better suited to the ever-changing needs of persons with Alzheimer's and their caregivers.

Chapter one provides an overview of the impact of Alzheimer's Disease on caregivers as well the effects the disease has had on the healthcare and social systems. Chapter two utilizes a literature review to discuss the purposes, utilization patterns, and barriers to institutional respite use. Chapter three is a description of the methodology used in the present study, including information about qualitative research and grounded theory. The study's data are analyzed and presented in Chapter four. Chapter five concludes the paper with a discussion that includes the limitations of the present study, an overview of the barriers to institutional respite, considerations for respite redirection, service alternatives, and recommendations for future research.

Chapter One:

The Caregiving Context of Alzheimer's Disease

Alzheimer's Disease (AD) was discovered in the late 19th century and was initially described as "a progressive degenerative disorder, insidious in onset, followed by gradual deterioration and death" (Cummings as cited in Dupuis, Epp, & Smale, 2004). Others have described Alzheimer's Disease as a completely devastating and eventually debilitating condition characterized by "a chronic, relentless, progressive deterioration in all functions, starting with short-term memory loss and impaired language and judgement, and eventually leads [sic] to complete disability and death" (Government of Ontario, 1999, p. 11). The disease causes an irreversible dementia wherein any of the following mental capacities can be compromised: language, memory, visual-spatial skills, emotion and personality, and cognition (abstraction, calculation and judgment) (Dupuis et al., 2004). There has been a great deal of research conducted, however, Alzheimer's is still considered to be an illness with no known cause or cure (Government of Ontario, 1999).

The Canadian Study of Health and Aging (CSHA, 1994c) estimates that over 364, 000 elderly adults in Canada have an illness causing dementia. Even more alarmingly, it is believed that one in thirteen Canadians over the age of sixty-five is affected by Alzheimer's Disease or a related dementia (Dupuis et al., 2004). In the province of Ontario alone it is estimated that more than 117,000 people live with the disease, 90 percent of whom are over the age of 65 (Government of Ontario, 1999). Although there are several causes of dementia in the elderly, Alzheimer's Disease is considered to be the primary cause (Government of Ontario, 1999; Dupuis et al., 2004), accounting for 75% of dementia in women and approximately 52% of dementia in men (Dupuis et al., 2004).

With the rapidly increasing older adult population, the number of persons living with dementia is expected to rise dramatically over the next several decades (Government of Ontario, 1999; Smale & Dupuis, 2004). Consequently, by 2010, the actual number of moderate to severe cases of dementia will increase by 85% and will increase even further to 150% by 2021 (Government of Ontario, 1999). By the year 2031, over three-quarters of a million Canadians are estimated to have Alzheimer's Disease or a related dementia (CSHA, 1994c).

Despite the prevalence of Alzheimer's Disease in persons over the age of 65, more and more cases of early onset dementia, where people experience symptoms in their forties and fifties, are being reported (Dupuis et al., 2004). While it is suggested that early onset dementia accounts for only 10% of all dementia cases, understanding its impact will become increasingly important as the needs of younger adults with dementia are likely to be vastly different from the needs of older adults (Dupuis et al., 2004).

Alzheimer's Disease is a difficult journey for those who have the condition as well as for their family and friends who love and care for them. This is by no means a stretch considering that 80-90% of care for Alzheimer's patients is believed to be provided by family members at home (Rudin, 1994). A similar statistic states that approximately half of the individuals with dementia in Canada live in the community and almost all, 94 percent, of them are cared for by family or friends (Dupuis et al., 2004).

Studies on caregiver demographics in North America show that the 'family and work model' still prevails despite the fact that this type of family organization, where the man works outside the home as breadwinner and the woman inside the home as homemaker and caregiver, is increasingly rare (Dupuis et al., 2004). While increasingly more men are taking on caregiving roles, women still represent the majority of Alzheimer's caregivers (Government of Ontario, 1999; Smale & Dupuis, 2004), with roughly 40% being spouses and 30% being daughters (Dupuis et al., 2004). A recent study conducted in Ontario reiterated these statistics by finding that 74.8% of caregivers were in fact women, predominantly wives and daughters (Smale & Dupuis, 2004).

Another major concern regarding caregivers is that almost half of them are over the age of 65, 25.4 percent of them 75 years or older (Smale & Dupuis, 2004). Consequently, it has been suggested that a significant number of caregivers will be facing various health problems associated with later life themselves (Government of Ontario, 1999; Smale & Dupuis, 2004). Combined with the physical and emotional demands of caregiving, elderly caregivers are at serious risk of experiencing further decline in their own health (Dupuis et al., 2004).

In terms of the primacy of caregiving, the literature seems to be rather inconclusive, with some suggesting that the majority of caregivers take on full caregiving responsibilities and others concluding that it is rare that one caregiver has no additional assistance from other family or friends. The most recent data from the MAREP (Murray Alzheimer Research and Education Program) study found that approximately one third of caregivers were providing sole primary care with no assistance from others and just over another third were primary caregivers with some assistance from others when needed (Smale & Dupuis, 2004).

Caring for a person with Alzheimer's is considered among the most difficult forms of caregiving (Cotrell & Engel, 1998) so much so that Alzheimer's caregivers are often referred to as the 'second victims' (Adler, Ott, Jelinski, Mortimer, & Christensen, 1993). The reasons for this are mainly due to the length and amount of time spent with the care-recipient as well as to the nature of the tasks performed (Flint, 1995). Further, as the care-recipient's ability to perform the daily tasks of living decreases, the amount of assistance required increases, usually reaching a point of caregiver physical and emotional exhaustion (Anthony-Bergstone, Gatz, & Zarit, 1988).

Alzheimer's caregivers spend, on average, 69 to 100 hours per week caring for their loved ones (Government of Ontario, 1999), doing everything from supervising to transporting to preparing meals to arranging services to administering medication to helping with feeding, dressing, bathing and continence (Dupuis et al., 2004). The commitment to constant care can carry on for some time as the reported average number of years spent caregiving before placement or death is 6.5 (Dupuis et al., 2004). Others assert that it is not uncommon for caregivers of persons with AD to provide increasing levels of care for ten or even twenty years (Rudin, 1994), and this is often in addition to caregivers' other responsibilities such as work and their own families.

Needless to say one of the major stresses of Alzheimer's care is the lack of time for oneself (Flint, 1995; Smale & Dupuis, 2004), and even if caregivers do get time away from the care-recipient, they find that the guilt and worry they experience greatly interferes with their ability to enjoy themselves (Novak & Guest, 1989; Smale & Dupuis, 2004). Other stresses reported by caregivers of persons with Alzheimer's include the feeling of being responsible for care, concern for the welfare of their loved one, concerns over the limitations caregiving has put on their lives, the physical and emotional demands of care, the worrying about the financial costs of caregiving (Smale & Dupuis, 2004), and the list goes on and on.

[There is one important factor that distinguishes caregiving for someone with Alzheimer's from other types of caregiving and that is what has been termed "ambiguous loss", which occurs when the care-recipient is perceived by the caregiver as being physically present, but psychologically absent from the relationship (Smale & Dupuis, 2004). Others have referred to this phenomenon as the patient's "loss of self", that is the severe personality and behavioural changes and memory loss that interfere with the bond the family members had experienced before the progression of the disease (Rudin, 1994). The impact of caring for someone they know and love and at the same time having to redefine that relationship because that person no longer knows or relates to them in the same way is absolutely devastating to Alzheimer's caregivers and therefore greatly contributes to the amount of caregiving stress (Dupuis et al., 2004).]

In summary, Alzheimer's caregivers experience particularly high levels of stress and burden, which is why they also have a high prevalence of psychiatric disorders, in particular depression and anxiety (Flint, 1995). Studies show that depression is nearly twice as common in persons caring for someone with dementia as in other caregivers (Dupuis et al., 2004). Unfortunately, Alzheimer's caregivers rarely get a break from their stressful care situations, and it is often a result of their own "resistance" to outside help. Informal caregivers of persons with Alzheimer's Disease have reported that community-based services, respite services in particular, are essential to decreasing their levels of stress and helping them fulfill their caregiver roles, yet, despite their importance, these services remain highly underutilized (Cotrell & Engel, 1998).

Chapter Two:

Literature Review

Respite Purposes, Utilization Patterns, and Barriers to Use

The concept of respite care was first established in Britain in hospital settings (Adler, 1992) and later in the United States as a corollary of the de-institutionalization movement in the early 1970's for adults and children with developmental disabilities (Montgomery, 1995). A universally accepted definition of respite does not exist (Brody, Saperstein, & Lawton, 1989) and for that reason, there appears to be issues with the conceptualization of what respite is and what it should accomplish (Spence & Miller, 1986). Generally speaking, respite has been recognized as a mechanism for encouraging family caregiving (Berry, Zarit, & Rabatin, 1991). It is designed to reduce caregiver stress and burden, thus facilitating the caregiving process and postponing or avoiding costly nursing home placement (Flint, 1995).

Respite has been operationally defined as:

> "...ongoing relief for the families of clients being cared for at home, may be on an hourly or daily basis, or for several days. Respite care can be provided in or out of the home, as day care or overnight care. It is a unique service in that it provides benefit from the time off;...Clients benefit from socialization and stimulation, being with their peers, doing activities targeted to their level, and spending time with trained caregivers who have time to interact with them. When they return home, the clients benefit from being with a refreshed caregiver whose energy level has been renewed. All respite programs appear to have a common goal: delaying institutionalization"
>
> Grasel, 1997: 438

One of the difficulties in characterizing respite is the confusion over whether services should be directed towards the health needs of the care-recipient or the physical, mental and emotional needs of the caregiver (Spence & Miller, 1986). In the case of families dealing with Alzheimer's disease, the general consensus is that respite is primarily concerned with alleviating caregiver stress while, at the same time, providing some benefit to the care-recipient as well, although it is not certain whether the care-recipient directly benefits from the respite program or indirectly from the extent that the respite reduces the caregiver's level of stress, enhancing the quality of interaction between the caregiver and the care-recipient (Adler, 1992; Lawton, Brody, & Saperstein, 1989a; Montgomery et al., 2002).

A second difficulty in defining respite is the multitude of forms it can assume (Montgomery, 1988). Respite can be formal or informal, it can take place in a hospital, nursing home, long-term care facility or other institution or it can be provided in the family's home, and it can be offered on a short-term or long-term basis (Montgomery, 1995). The present review is concerned with formal services, which are normally paid for by families, by the government or, quite often, a combination of both.

There are essentially three main classifications of formal respite intervention: out-of-home community care (mainly day programs), in-home care, and institutional care (Lawton, Brody, Saperstein, & Grimes, 1989b; Montgomery, 1995). Gottlieb and Johnson (as cited in Dupuis et al., 2004) outline the three types of respite as follows:

> "1. *Centre-based adult day programs/services*, which include congregate care for a number of hours per week, depending on the needs of the caregiver and the program characteristics;
> 2. *In-home or domiciliary respite*, which provide relief in the home by workers with the qualifications and training suits to the person with dementia; and
> 3. *Institutional respite and vacation/emergency respite*, which includes round-the-clock substitute care, usually in a long-term care facility..."
>
> Dupuis et al., 2004: 40

The three types of respite are not in competition with one another, rather they are used quite differently by different types of caregivers with different needs and preferences (Dupuis et al., 2004; Lawton et al., 1989b). For example, women, daughters even more so than wives, are more likely to use all forms of respite (Smale & Dupuis, 2004); this may be a result of women's involvement in more cohesive care networks, meaning that they are more likely to be in contact with other caregivers and would know of others who have successfully used respite in the past, although further research would be needed to support this notion (Willis, Allen-Burge, Dolan, Bertrand et al., 1998).

Compared to women, men use respite services rather infrequently (Montgomery, 2002). More recent research by Dupuis et al. (2004) found that male caregivers who do use services, express a need for home health care and in-home respite above any other service (Smale & Dupuis, 2004), but none of the present literature provides a detailed explanation as to why this may be the case. Overall, very little can be concluded about male caregivers' disinterest in or reluctance to using respite services, and even less can be concluded about how male spouses and male adult-children differ in their patterns of respite use, and until the number of male caregivers begins to increase, the research in this area will remain limited.

Another area in which the literature is substantially lacking is in assessing the impact of racial and socio-economic factors on respite utilization. In one study, it was found that Black families were less likely than white families to continue to use services after an initial assessment had been made, which is why it is so important to work along side minority families to ensure that there are no real or perceived barriers to service use

(Deimling and Looman (1990). Deimling and Looman (1990) also found that caregivers of colour showed a preference for day respite over homecare services, possibly because these caregivers were slightly more likely to be adult children and employed, both of which are potential factors in choosing one form of respite over another. Clearly, Black families are not the only ethnic groups in a position to seek or use respite services, and with exception of a few studies briefly mentioning Hispanic families in the US, ethnicity, culture, and socio-economic background have largely been ignored in studies on respite utilization.

There are also significant differences between spouse and child caregivers. Adult-child caregivers are less likely to use respite services than spouse caregivers, but once child caregivers begin using services they use a far greater volume of services than spouse caregivers (Deimling & Looman, 1990). Child caregivers' reasons behind service use also differ from those of spouse caregivers. Adult-child caregivers, predominantly women, view respite as an opportunity to tend to other obligations, namely work and the needs of their own children, whereas elderly wife caregivers view it as a break from the demands of caring for their spouse (Deimling & Looman, 1990). As a result of the convenience of daytime care hours, adult-child caregivers prefer day program respite, whereas spouses may get more relief from care provided in the home for a few hours daily (Deimling & Looman, 1990). Further, older caregivers tend to provide more intimate or hands-on care than children do, thus benefiting from the kind of assistance home healthcare provides (Montgomery, 1995).

The progression of Alzheimer's Disease itself can also affect utilization patterns (Montgomery et al., 2002). Firstly, caregivers often feel less guilty about 'subjecting' their loved ones to respite when the disease is in the mid to advanced stages and the care-recipient is less aware and less able to perform the activities of daily living, particularly bathing and toileting (Smale & Dupuis, 2004). Secondly, day care services are more likely to be used in the early stages of the disease as the programs cannot accommodate persons with advanced needs and behavioural problems, whereas home care services can be used at any time (Dupuis et al., 2004; Lawton et al., 1989b). Lastly, institutional respite is used in the later stages of the disease, normally as a last resort or as a precursor to permanent long-term placement (Montgomery et al., 2002), mainly because as the care-recipient loses more of his or her physical and cognitive abilities, a nursing home or long-term care facility environment tends to seem less inappropriate than it does in the early stages of the disease (Kosloski, Montgomery, & Youngbauer, 2001).

Each of the preceding types of respite have both advantages and disadvantages. Day away programs and institutional respite are seen as having the advantage of allowing caregivers to remain in their homes, enjoying time alone or with other family members or friends, hopefully eliminating some of the caregiver's feelings of isolation as well as burden (Montgomery, 1995). Homecare is more flexible than institutional respite, but is more expensive, relatively speaking; the only reason institutional care is seen as being so costly is because the stays are usually longer (Montgomery, 1995). Home care has the advantage that caregivers do not have to arrange for transportation and that their overall preparation time is significantly minimized (Montgomery, 1995).

In terms of disadvantages, day programs have stricter eligibility requirements and cannot accommodate persons with high needs, they are available only during daytime hours and on weekdays, and they do not account for problems specific to geographic proximity and transportation (Dupuis et al., 2004). In-home respite also causes problems in that it is not usually available in the evenings or on weekends or in a time of crisis, there is often a high turnover of staff, and some caregivers view in-home services as an invasion of their privacy (Lawton et al., 1989b; Montgomery, 1995). Institutional respite has disadvantages as well, including a lack of availability, the amount of preparation time required, and the cumbersome regulations associated with institutions (Dupuis et al., 2004).

For caregivers of persons with Alzheimer's Disease, the most frequently requested service is in-home respite, provided for short periods of time (Montgomery, 1995). Currently, the most frequently used service by caregivers is day centre programs specifically tailored to meet the needs of persons with Alzheimer's and other dementias (Smale & Dupuis, 2004), and the least used service out of all respite services offered to Alzheimer's clients is institutional respite (Lawton et al., 1989a). Studies have shown that a large percentage of dementia caregivers do not use formal services even if they are available to them free of charge (Brody et al., 1989; Montgomery, 1988). Respite is to be seen as a preventative service (Lawton et al., 1989a), however, caregivers use respite too infrequently and too late in the caregiving trajectory for a true assessment of their preventative or overall value (Dupuis et al., 2004).

Even though Alzheimer's caregivers have identified respite as one of their most pressing needs, there continues to be evidence of reluctance, underutilization, delayed and inappropriate use of services (Feinberg & Whitlach, 1998). It is, therefore, essential to conduct research that examines why caregivers seek or do not seek information about services and why they do or do not take advantage of services of which they are aware (Kosloski et al., 2001).

Rudin (1994) outlines four predictors of respite use, which include: availability, accessibility, quality, and utility. Availability refers to whether programs exist in the caregiver's community, caregivers' awareness of services, program eligibility requirements, scheduling that meets caregivers' needs, and whether there are program openings; accessibility includes items such as transportation, proximity, and cost; quality includes the perceived quality and auspices of the service, whether or not it seems like a friendly and safe environment, and if the program is easy to use, and; utility refers to whether the caregivers' perceive the service to meet their needs as well as the needs of the care-recipient (Rudin, 1994).

The Anderson-Neuman model is perhaps the most widely used tool in examining service utilization patterns. The model sets out three variables as predictors of use: predisposition, enabling factors, and need (Braithwaite,1998; Cox, 1997; Deimling & Looman, 1990; Montgomery, 1995). Predisposition refers to factors that interfere with caregivers taking advantage of available services; these factors can be either personal or structural (Cox, 1997). Enabling factors refer to resources, including a lack thereof, which can affect caregivers' access to services; these are primarily things like availability, funding, and service costs, but also includes the nature of the care relationship and the physical and emotional aspects of the care environment (Cox, 1997; Deimling & Looman, 1990). Need refers to the functional status of the care-recipient, the demands on the caregiver, the physical and mental health of the caregiver, and the caregiver's degree of perceived burden (Cox, 1997).

The main point to be emphasized with both of the above models is that, ultimately, the decision (to seek or not seek and to use or not use) formal respite services depends almost entirely on a decision-making process on the part of the caregiver (Adler, 1992). Respite care usage is a decision dementia caregivers have to make on their own as the care-recipient is often unable to participate; caregivers initiate the process, decide when and what services to use, determine if the services meets their needs and the needs of the patient, and decide whether or not they want to continue using services (Adler, 1992).

Essentially, there are three main categories of barriers to the use of respite services for Alzheimer's caregivers: 1) caregiver-related barriers 2) disease-related barriers, and 3) systemic/service system barriers (Grasel, 1997). The first types of barriers are those that derive from the caregivers. Two main items affect caregiver barriers: the caregiver's relationship with the care-recipient, and the caregiver's perception of need and subjective well-being. The first item, the caregiver/care-recipient relationship, has an enormous impact on the decision to use or not use respite services. There is considerable evidence that a diagnosis of dementia actually predicts a worsening of the relationship between the caregiver and the care-recipient following the use of out-of-home respite, particularly institutional respite (Flint, 1995). This would explain why Alzheimer's caregivers prefer short-term, in-home respite as it has very little effect on the caregiver/care-recipient bond (Willis et al., 1998).

In terms of the relationship specifically, Willis et al. (1998) found that caregivers who scored highly on love and intimacy scales were willing to forego a sense of freedom from their caregiving role if it meant that the social bond between themselves and the care receiver was put at risk. The researchers interpreted this finding to mean that caregivers would rather continue caregiving, with the bond intact, feeling somewhat assured by the fact that respite would be available in a crisis (Willis et al., 1998). Brody et al. (1989) explain that some caregivers are 'pathologically invested' in not receiving assistance, they are totally enmeshed in their caregiving role and therefore use all kinds of excuses why they cannot use services (Brody et al., 1989).

Spousal caregivers, being part of one of the most intimate relationships, are especially vulnerable to overburdening themselves so as to maintain the bond between themselves and their loved ones with dementia (Gwyther, 1990). Dupuis and Smale (2004) did, in fact, find that spouses, when compared with all other caregivers, reported the highest levels of stress and burden. A partial explanation may be that couples definition of self and the relationship becomes threatened when one of the partners lives with dementia; family care becomes static and focused on one person, dependencies change and power is altered, caregivers feel responsible for breaking the bond, social isolation increases, and the care-recipient often shadows the caregiver giving the latter little sense of privacy (Gwyther, 1990). An important point to remember is that a positive and/or loving caregiver/care-recipient relationship does not translate into the caregiver feeling less socially isolated. Spousal caregivers report the highest levels of intimacy as well as the highest perceptions of social isolation (Willis et al., 1998).

'Separation-Individuation' is a term typically used in the context of spousal care relationships, but it could easily be applied to other intimate caregiving relationships as well (Gwyther, 1990). Separation-Individuation involves a situation where the caregiver has well-established values about commitment and family solidarity while simultaneously sensing that they have lost the "we-ness" between him/ herself and the person they love and care for (Gywther, 1990). Separation-Individuation is especially relevant to those caring for persons with AD because sometimes the caregiver gets a small glimpse of the person he or she once knew, therefore making it extremely difficult to let go or to give up care to someone else (Gwyther, 1990).

Caregivers view respite use as an abandonment of their loved one and a threatening of the familiar give-and-take relationship, they feel that they are being disloyal and that the separation is unnecessary (Gwyther, 1990). The individual who takes on the primary caregiving role is often the person closest to the patient, and as a result of this close relationship, the caregiver often feels guilty about choosing to use respite services (Grasel, 1997). Guilt, sense of responsibility, and betrayal of trust are probably the three largest barriers related to the caregiver/care-recipient relationship (Smale & Dupuis, 2004).

Caregivers will sometimes use services once they are at their breaking point, utilizing respite as a necessary physical distancing between themselves and the care-recipient or as a retreat from the stress (Smyer & Chang, 1999). These are caregivers who are intimately related to the patient and who finally decide that the respite is as much for the care-recipient as it is for them, as a protective measure, as a service that can deliver quality care without stress and conflict (Smyer & Chang, 1999).

Other caregiver barriers are related to the caregiver's perception of need (for services) and their subjective sense of well-being; well-being meaning their perception of how well they are coping with the responsibilities of caregiving as well as how physically and emotionally well they feel in general (Grasel, 1997). Caregivers of persons with Alzheimer's Disease essentially undergo a cost/benefit-type analysis, assessing whether or not the service is worth their time, effort, and money, and deciding whether or not the service is going to benefit them, and even more importantly, their loved one (Rudin, 1996).

The literature illustrates that the most common reason given by caregivers for not using respite is a lack of perceived need (Flint, 1995; Lawton et al., 1989a; Montgomery, 1995). Caregivers' perception of need is assessed by examining two things: the belief that support or assistance is required in one's current situation, and the belief in a particular service or set of services to remedy that requirement (Montgomery, 1995).

Caregivers who view themselves as being unwell or see themselves as being over-burdened by their caregiving duties do in fact use respite services (Grasel, 1997), the problem is that caregivers rarely see themselves as being unwell or over-burdened (Montgomery, 1995). Furthermore, caregivers have little faith in respite services' ability to significantly better their caregiving situations (Grasel, 1997). The literature undoubtedly supports the belief that respite use does nothing to permanently alter caregivers' levels of stress and burden; respite can temporarily reduce stress levels during the time of actual use, but levels return to normal immediately upon caregiver- care-recipient reunion (Grasel, 1997: Smyer & Chang, 1999).

The second types of barriers are those related to the disease, specifically the fact that persons with Alzheimer's dementia need familiarity, structure and routine, they have special safety concerns due to memory loss and the tendency to wander, they have extremely high physical care needs, and they often require 24 hour a day assistance (Dupuis et al., 2004). Caregivers are reluctant to use services because they fear that they will negatively affect the care-recipient's mental, physical and emotional states (Flint, 1995). Caregivers fear that their loved ones will suffer from the 'trauma of relocation' (Spence & Miller, 1986) as a result of going from a familiar environment to an unfamiliar or strange environment. Caregivers seem to feel more comfortable with exposing the care-recipient to a temporary, unfamiliar caregiving situation when the latter is further along in the disease, meaning that they are less aware of the changes in environment (Brody et al., 1989).

Caregivers fear that respite programs cannot adequately deal with the inherent needs of individuals with Alzheimer's Disease. For example, caregivers worry that the behaviours and physical needs of the care-recipient are too difficult for respite care, that programs are not equipped to deal with things like aggression, immobility, incontinence, wandering, and an inability to communicate (Grasel, 1997). Caregivers also feel that no one knows their loved one better than themselves, and therefore no one can provide as good of care as they can, and unfortunately, there is a significant amount of truth to this notion (Dupuis et al., 2004).

The third types of barriers are those that stem from the service (delivery) system, which include: a lack of government funding for services, service unawareness and inappropriate timing of service initiation, program unavailability and inaccessibility, and the inability of programs to meet the needs of Alzheimer's clients and their caregivers (Grasel, 1995). Like many other forms of services for the ill elderly, respite services, too, have been subjected to the cost-effectiveness trap which has led to cuts in funding and in turn a decrease in the amount and quality of services (Montgomery, 1995). Current respite services appear to be based on what is available rather than on the specific and changing needs of caregivers (Dupuis & Smale, 2004).

The service system is inflexible (Dupuis & Smale, 2004) and operates in a way that leaves caregivers with an extremely limited sense of choice and control, which directly affects their desire to use services; caregivers want a system where there is potential for individualization of services (Feinberg & Whitlatch, 1998). Services are most supportive when they can be tailored to the unique challenges of dementia patients and caregivers, when they recognize that the experience of Alzheimer's Disease can be very different for different families (Smale & Dupuis, 2004); respite care is not a situation of 'one size fits all' (Deimling & Looman, 1990).

A summary of service system barriers has been comprehensively outlined in a recent study by Smale & Dupuis (2004). The results show that caregivers consider the service system in Ontario to be economically focused, which has resulted in the following: a decrease in the quality of services provided, an unacceptably low number of trained workers, an inadequate number of available service hours, services that do not meet the needs of caregivers or care-recipients, a system too difficult to understand or navigate, services which are too difficult to obtain due to bureaucratic procedures, a fragmented delivery system where people often 'fall through the cracks', services that are too expensive for many families, and a system which is run from the top-down with little input from the persons who provide everyday care to persons with Alzheimer's Disease (Smale & Dupuis, 2004).

The three classifications of barriers, caregiver-related, disease-related and service system-related, are by no means mutually exclusive. For example, the caregiver barriers are inevitably affected by the service system as well as by the individual with Alzheimer's, and the caregiver barriers would, in turn, affect both the service system the individual living with the disease, and some barriers cross over all three classifications (Spence & Miller, 1986).

The impact AD has had and is expected to have on individuals as well as on the health care system is enormous. In response, a great deal of funding has gone towards research, demonstration projects, and several other initiatives. The Government of Ontario, specifically, has responded by implementing a comprehensive provincial Alzheimer strategy for the future, making the province a leader in the area of Alzheimer's care. In 1989-1999, as part of its $1.2 billion multi-year investment, the Ontario government proposed that roughly $68.4 million would be invested in a multi-faceted strategy for Alzheimer's Disease (Government of Ontario, 1999). The areas of investment include: staff education and training, physician training, public awareness and education, planning for safe and secure environments, respite services, research on caregiver needs, advanced directives on care choices, psychogeriatric consulting, diagnosis and support, and intergenerational volunteer support (Government of Ontario, 1999).

Direct pay or consumer-directed models of respite are another way the government has invested in Alzheimer's Disease. Direct pay models involve a certain amount of funding to be given directly to the caregiver to make individual choices about who provides care to their loved one and in what manner (Feinberg & Whitlatch, 1998); this model has been applied primarily to in-home respite. Another item that has been introduced into the policy arena has been caregiver compensation programs, where the government provides financial assistance to family members who have chosen to provide care (Linsk, Keigher, England, & Simon-Rusinowitz, 1995). Both of these programs would resolve at least some of the caregivers concerns over choice and control, though these programs are rarely implemented.

Current research on Alzheimer's Disease and respite use needs to focus on the ways in which respite users move through the service system, from inquiry about services to assessment for services to the actual use of service, and finally, to the evaluation of services (Deimling & Looman, 1990). Policy makers are quick to conclude that respite services only moderately affect caregiver stress and burden and that they do very little to delay institutionalization, but respite services have often been studied in ways which it is impossible for the desired effect to occur (Deimling, 1991). Methodologically, there have been limited controlled or comparison group studies, studies that compare users and non-users (Lawton et al., 1989a), and even fewer longitudinal studies that assess the long-term affects of various types of respite intervention (Dupuis et al., 2004). Small sample sizes and samples that are unrepresentative of the general caregiving population also present important methodological difficulties (Rudin, 1994).

Generally speaking, the research on Alzheimer's respite services has focused more on caregiver and care-recipient social and demographic characteristics and less on caregiver personal beliefs, values, and preferences (Rudin, 1994), which is simply unrealistic given that the caregiver is the ultimate decision maker on whether or not services are utilized. Further, caregiver voices have largely been excluded in research that can potentially change policy and, in turn, service provision (Dupuis et al., 2004); this is not only unrealistic, but unjust, given that caregivers are the people who make enormous life sacrifices on an everyday basis to ensure that their loved ones are cared for.

Specifically speaking, research on Alzheimer's Disease needs to include an examination of the extent to which caregivers are aware of, make use of, and are satisfied with formal respite services (Dupuis et al., 2004). The research should also help to understand the perceived constraints, barriers and challenges that caregivers experience as they attempt to access services, and how the system can work to alleviate some of these barriers. The research should include an understanding of the caregiver/care-recipient relationship as it applies to the caregiver's decision to use or not use services (Willis et al., 1998). Overall, future research on respite use for Alzheimer's clients should provide an understanding of the effectiveness or ineffectiveness of the various types of formal supports with the intention of significantly improving the caregiving experience (Dupuis et al., 2004).

There has been a tendency for studies to group the three forms of respite together, with the assumption that barriers to the use of respite in general somehow applies to day, in-home, and institutional respite equally. The current article contains findings that deal specifically with the barriers to the use of institutional respite, although attention is also given to the differences between day, in-home and institutional respite, the fit or non-fit of institutional respite for persons with Alzheimer's Disease, caregiver understanding of respite services, and how respite services can better accommodate families living with Alzheimer's Disease.

Chapter Three:

Methodology

Research Design

The purpose of this study is to explore the perceptions of key people involved in the use of respite services by families living with Alzheimer's Disease. The research identifies and examines the factors that influence caregiver's utilization or non-utilization of formal respite services, particularly long-term institutional respite. This study's methodology is guided by the fundamental principles of qualitative research and the more specific techniques of grounded theory (Strauss & Corbin, 1990).

Qualitative research methods are used when more personal sources of data are sought (Murphy & Longino, 1992). Qualitative techniques allow the richness of people's experiences, perceptions and personal meanings to emerge as part of a shared experience between the participant(s) and the researcher (Berg, 2004). Further, qualitative methods generally adopt a more holistic approach, considering the social and environmental context of situations as well as the individual experiences of the participants (Patton, 1988).

Grounded theory is considered an important part of qualitative research as it is "based on the premise that the meanings that people give to the events in their lives are very important in understanding their responses and resilience to the events. It is based primarily on theories of symbolic interaction, which holds that people construct their own meanings for events based in part on their interactions with others" (Yegidis & Weinbach, 2002:142).

Qualitative methods are oriented towards exploration, discovery, and inductive logic (Patton, 1988). Inductive research design differs from the traditional experimental-deductive approach in that it begins with specific observations and builds toward general patterns (Patton, 1988). In grounded theory, the researcher does not begin with a theory and then proves it; he or she begins with an area of study to be explored , then data collection, analysis and theory are conducted simultaneously so that what is relevant to that area will emerge naturally and gradually (Strauss & Corbin, 1990).

Given the high level of topic sensitivity, qualitative research was considered the most appropriate manner in which to conduct the present research. I felt that in order to uncover the true barriers to the use of institutional respite, the voices of key individuals, primarily caregivers, but also professionals involved in the use of formal services, needed to be heard. I believed that the best way to gain a comprehensive understanding of people's social situations and personal processes was to ask them, through way of qualitative research methods.

Sampling

This study used a purposive sample in order to ensure that certain types of participants displaying certain attributes were included in the study (Berg, 2004), namely caregivers as well as professionals involved in assisting caregivers with the decision to use or not use respite. For present purposes, the term 'caregiver' will refer to an informal, unpaid family member who provides care for a person with Alzheimer's Disease.

For the caregiver participants, I wanted to interview people who had used day respite, but not long-term institutional respite, so as to assess why caregivers who use short-term respite do not use long-term respite as well. I approached Sunnyside Home as they were the only facility in Waterloo Region that housed a day, weekend and long-term respite program for Alzheimer's clients. The co-ordinator of the day program contacted several clients to inform them of my research and then allowed the clients to choose whether or not they wanted to participate. The co-ordinator gave me a list of six people who were interested in participating in my research, five of which I contacted to confirm participation. The sixth potential participant was going to be on vacation at the time the interviewing was to take place therefore I did not contact him or her.

The caregiver sample was purposely not controlled for variables such as race, gender, age, income, level of care provided, burden level, and so on as the sample size was too small and also because I wanted to allow whichever "type" of caregiver to come forward. The final caregiver sample resulted in three of the caregivers being spouses, two husbands and one wife, and two of them being children, both daughters.

As a result of, primarily, the small caregiver sample, but also the need for relevant professional input, I wanted to include two professionals who work with caregivers everyday, helping them to make decisions around the use of respite services. The professional participants were purposive, but were also somewhat of a convenience sample; the social worker at Sunnyside was the only one I could interview who wasn't involved in my research, and the CCAC worker was referred to me by the co-ordinator at Sunnyside.

In grounded theory research, sample selection is done simultaneously with data collection and data analysis; this means that early data help shape subsequent sample selections and research focuses (Yegidis & Weinbach, 2002). The present study's sample changed several times during the research process. Initially, the sample was to include three caregivers, three care-recipients, and two formal service professionals employed at Sunnyside Home. The non-professional participants were to be families who utilized the Sunnyside day away program, but not the weekend or long-term respite. For purposes of this study, long-term respite refers to a stay of a minimum of two nights in a long-term care facility.

Before the research began, care-recipients were excluded as participants as they were considered to be too impaired with dementia to participate and for fear of potential unnecessary psychological harm to them resulting from discussions around institutionalization. As the research progressed and data was analyzed, several other changes occurred in the sample. The first change was the inclusion of one participant who presently uses respite, but was reluctant to do so for years. The second change occurred after a number of caregiver participants repeatedly mentioned CCAC (Community Care Access Centre) as having both a positive and negative impact on their utilization of services; this resulted in the interviewing of a CCAC case manager in place of a second Sunnyside employee.

In the end, the sample consisted of five caregivers, one who was using all three forms of respite services, including institutional respite, and four who were using the day respite, but had never used long-term institutional respite, one social worker employed in the admissions department at Sunnyside, and one Waterloo Region CCAC case manager; seven participants in total.

Data Collection

Prior to approaching the participants, approval to conduct the study was obtained from both the McMaster University Ethics Board and the Board of Physicians at Sunnyside Home.

Data collected in this study were cross-sectional, wherein relevant variables were assessed at a single moment in time, and examined simultaneously or as close in time as possible (Yegidis & Weinbach, 2002). As was mentioned in the sampling section, the participants were recruited with the cooperation of the day program co-ordinator at Sunnyside; this was considered the most sensitive way to approach potential respondents as I was at stranger to them at this point. After participants agreed to participate, I contacted them by telephone to introduce myself and to give them a chance to tell me about themselves, to inform them of the research procedures, to confirm their willingness to participate, and to set up an interview time and place.

Participants were given the choice of where they wanted to be interviewed, depending on what was most convenient and comfortable to them. Some were interviewed in their homes while others were interviewed at Sunnyside. Prior to the interview, each participant was reassured of the confidential nature of the information to be provided. Participants were informed of their rights as a voluntary interviewee, and were asked to sign a consent form to verify his or her understanding of the research proceedings (Appendix A). Participants were also given a letter of information as a source of reference, providing contact numbers if they should have any present or future questions about their participation in the study (Appendix B). The interviews were conducted in June and July of 2004, and were approximately one hour in duration. All of the participants consented to be tape-recorded during their interviews.

Instrumentation

An in-depth, semi-standardized (Berg, 2004) interview guide was prepared for the caregiver and staff participants (Appendix C and D, respectively). Semi-standardized interview guides were used to provide some structure to the interview, while still providing latitude for the participants to share their experiences and perceptions freely. Although I was looking for answers to specific questions, how the questions were worded was done with as much neutrality as possible, the questions were not asked in a particular order, the wording of the questions was flexible, probes could be used or not used or changed, and some questions were not asked as the information was received in an answer to another question.

It was important for me to provide a framework within which people could respond comfortably and honestly to open-ended questions, which is why I began the caregiver interviews with a general question about stress and how it relates to caring for someone with AD, thinking this would build some rapport and would allow the caregivers to share some of their general issues before delving into the more specific items dealing with respite. In general, the interviews were informal and participant-driven, and included some elements of an informal conversational interview (Patton, 1988), while keeping some structure by way of the interview guide.

The interviews sought to uncover information in a number of key areas:

1) The perceived impact of Alzheimer's Disease

2) The perceived difference between day, in-home, and institutional respite
3) The perceived fit or non-fit between respite services and the needs of families
4) The perceived barriers to respite service utilization
5) Changes that would better accommodate families dealing with AD

Data Analysis

Acquiring grounded knowledge involves constantly monitoring and reshaping developing theories, it is a recurring process of proposing and verifying (Yegidid & Weinbach, 2002). In accordance with this approach, the data collected from the interviews of the present study were processed in a way that involved a continual process of conceptualization, comparing similarities and differences, identifying common themes, and developing categories and relationships (Patton, 1987). The interviews were transcribed, in full, using a word processing program, which aided in the progression of the analysis. Also, permission to be re-contacted was asked of the participants, and was used on an as-needed basis as a way of establishing trustworthiness.

The data initially underwent a process of 'open coding', which involved examining sentences and phrases, sometimes even single words, and grouping together related concepts into categories and properties (Strauss & Corbin, 1990). Following the process of open-coding, connections between categories and sub-categories were established by considering casual and intervening conditions, phenomenon, context, action/interaction strategies, and consequences; this is referred to as 'axial coding' (Strauss & Corbin, 1990). And finally, the data were analyzed by using 'selective coding' methods which involved choosing a core category and then systematically relating it to other categories, validating the relationships, and filling in the categories that needed further modification and/or development (Strauss & Corbin, 1990).

Theoretical sensitivity, which involves periodically stepping back and looking at the data, removing one's own prior knowledge and accepting that the data takes precedence over one's own agenda (Strauss & Corbin, 1990), was strongly implemented. Having had previous work experience with Alzheimer's clients, I had to abandon my prior assumptions and allow the information given by the participants to dictate the direction of the analysis.

Chapter Four:

Findings

The barriers associated with the use of institutional respite can be grouped into three main areas: 1) Caregiver Related Issues, 2) Disease Related Issues, and 3) Service System Related Issues. These three areas will serve as a way of organizing the categories of data that has emerged from the study. Each category reflects sub-categories or properties, which will provide further detail into what Alzheimer's caregivers identified as being the barriers to the use of long-term respite (see Table 1 for a summary of categories and properties).

The use of quotations from both caregivers and service professionals will be used not only to support the researcher's interpretation of the data, but also to allow the voices of the participants to essentially speak for themselves (Dupuis & Smale, 2004).

Category#1: Caregiver-Related Issues

A number of issues related to the underutilization of institutional respite services could be classified as being caregiver-related. The caregiver issues generally reflected three main categories: sole responsibility; feelings of guilt; and caregiver/care-recipient bond.

A. Sole responsibility

All of the caregivers expressed a sense of obligation in being the primary caregiver, although this was not described in a negative way. The reasons as to why they felt obligated to provide the majority of care centered around cultural beliefs, family values and ideas about (family) relationships and a responsibility to take care of the people you love. One caregiver, who was caring for both her parents, in her home, shared how culture and family values had deterred her from using long-term respite:

> *... because of the culture, culture is very huge, it's very big. My father saw his sister take care of his mother, so he expects us [the caregiver and her husband] to do the same for them [the caregiver's parents]. My husband is not European, and his parents are very independent. Now his mother has bipolar, but his father takes care of her, and they don't have the children brought in, the daughters aren't helping, if anything, they would probably go into a home before they would have their children help, that's just their culture...*

Four of the five caregivers reported that family conflict, particularly criticism and lack of involvement from other family members had severely increased their amount of responsibility. The lack of assistance only made them feel more responsible for providing care as there was a feeling that if they didn't do it, no one would.

Some of the caregivers mentioned that the care-recipient had either cared for them in the past or that they would care for them now, or both, and that is why they had no hesitation in providing care; the explanation was that the care they (the current caregivers) were providing and the sacrifices they were making was something that has been or would be reciprocated by the care-recipient if the situation were reversed. One caregiver explained, "my mom wouldn't have let me get naked, so why would I let her... she wouldn't have let me leave the house with a stain on my shirt..."

Three of the five caregivers stated that they would not use institutional respite services as long as they were able to care for their loved one themselves. Two of the caregivers were already retired, but the other three considered caring for their loved to be their sole responsibility so much so that they had quit their own jobs and become full-time caregivers to their family members.

The decision to use or not use respite services was also seen as an extension of the caregivers' sole responsibility. Four of the five caregivers stated that they had never directly spoken with the care-recipient about the disease and the problems it had been causing in their lives, and only two said that they had had a conversation about any respite services. Therefore, it appeared that caregivers were making decisions about respite without input from the care-recipient.

B. Feelings of guilt

All seven participants mentioned guilt as a factor in caregivers not using institutional respite. In fact, guilt was the most frequently mentioned issue by caregivers in explaining why they did not use respite. The participants explained the guilt as being related to caregivers' feelings that they would be abandoning their loved one, that they weren't doing their job or that they had given up, that they would be making the care-recipient go somewhere they did not want to go, or that they would be subjecting their loved one to inadequate care.

1. Abandonment

Caregivers felt that they were abandoning their loved ones by placing them, temporarily, in an institution. One caregiver described her fears about what might happen if she were to take her husband to stay in long-term respite:

> *...If he was really with it, it would be like' my god, no bloody way, what am I doing here?'...he might rebel, he might not, he probably wouldn't until I got there, and if I left him and said 'well, I'm going now', he'd be like, 'huh?'...I don't think I'd be able to relax knowing I'd pushed him, I don't think I'd be able to enjoy myself knowing I'd pushed him to get there because I'd be wondering what's it like ...it's partly guilt and partly putting myself in his place, I wouldn't want someone to drop me off and say, 'I'll see ya'.*

All of the caregivers, and one professional spoke about the caregiver's sense of guilt related to them abandoning their loved one just because he or she had dementia. Caregivers reported that even though they felt that they had lost the person they once knew, they still felt very attached to him or her; this was expressed as being an issue in deciding to use respite of any kind. The caregivers all said that they would have less trouble using respite if their loved one were extremely different from the person they had known and loved. One caregiver said, "It's a form of guilt, you know just because he's changed and is getting dementia, he's still the same person, still got the same personality I would have no problem [using respite] if he weren't aware, it wouldn't be an issue then".

2. Going against care-recipient's wishes about institutionalization

All of the caregivers expressed guilt around using institutional respite because they knew their loved one did not want to be put in a home. Four of the five caregivers stated that their loved one had specifically said that they did not want to be put in an institution as they were seen as being "homes for old, old people". All of the participants admitted that long-term care facilities had a negative stigma attached to them. Caregivers used phrases such as "the end of the world", "the beginning of the end", and "locked away" when describing institutionalization. It appeared that institutional respite, while temporary, was seen in a similar light to long-term placement in an institution.

An additional problem with institutional respite is that the application for temporary respite and long-term permanent placement are the same, and caregivers expressed being uncomfortable with this.

3. Fear of inadequate care

All but one caregiver identified a fear of inadequate care as being a major reason why they did not use long-term institutional respite. They spoke specifically about the lack of staff, lack of attention, and lack of direct care their loved one would receive as the main issues. One caregiver gave a detailed description of her fear of subjecting her mother to care in an institution:

> *I don't take her to respite because I'm afraid she's not going to be able to handle it correctly, she is a very demanding individual, whoever then would be looking after her would have to like constantly be alert to her, if she fell off the bed or anything happened...because she doesn't really, really, really makes sense, I mean a lot of these people don't speak German so when she's talking, they won't know...I know when she's looking for a Kleenex to blow her nose or I know when she's gonna get out of bed to go to the bathroom...I don't know, I feel uncomfortable... I guess a couple of concerns, one is the fear of somebody looking after her, because I know that I am a very, very patient person...you have to have patience and I don't know that these people would have the patience for her, and then if there's other people there, how much time are they going to spend with her?...unless I was absolutely, absolutely desperate, I don't think I would use respite, mainly because I'm afraid.*

Other caregivers were concerned about the one bath a week their relative would be receiving, about their loved one not being fed, and about the lack of activity their loved one would experience while being cared for in an institution. The caregiver who began using services after two years of reluctance, still did not think services were adequate:

> *I pay for a lady to come in from 5-9 for the five days that she's there. That lady feeds her, puts her to bed, gives her a bath, takes her down to some of the facilities, otherwise she wouldn't have them, and that's pretty sad...so I think about all of this...if I never had that girl coming in from 5-9, I'm pretty well sure I would not put her into respite...that makes me feel content, I can go away and there's no worry.*

C. Caregiver/care-recipient bond

1. Trouble letting go over time

All of the participants mentioned that caregivers have a great deal of difficulty "letting go" or "detaching" themselves from the care-recipient, even if it is just for a temporary period. One caregiver explained his hesitation in using long-term respite in very simple terms: "I couldn't see myself being away from her for seven days to tell you the truth". One professional stated, "We definitely see that mutual dependence, that engraved role, it's hard for them to let go, and that's more challenging for staff..."

It appeared that the caregivers viewed the length of time away from their loved one as a significant factor in deciding not to use institutional respite. All of the caregivers described having very loving relationships with the care-recipient, which made it difficult to make the decision to leave them in a home for a longer period of time. Many of them stated that they had gone through the same feelings with the day program respite, but because it was for a shorter period of time, the separation-related feelings were easier to deal with.

2. Emotional history

One of the professionals explained that caregivers worried about putting their loved one into long-term respite because of the lack of emotional history between the care-recipient and staff:

> *...and nobody knows them as well, and that's absolutely true, and nobody knows the history...that this person was a kind, loving, caring... lovely sense of humour, but now, they've lost all of that...but to know the background, you approach them with such empathy and so I think that's very difficult for families cause they're seeing the person in a different way than somebody else would and they just want to make sure that whoever is looking after them is treating them with respect...they want to know, will my loved one be cared for by someone who really understands?... and absolutely, the care [from caregivers] is better, the public purse couldn't afford that kind, that level of care.*

All of the caregivers worried that the care in institutional settings was not as good as the care they were providing at home, and some specifically mentioned that it was, at least partially, due to the fact that they knew this person better than anyone. One caregiver said, "she [the care-recipient] is comfortable with me, although I'm just a person to her, I'm with her all the time".

Category#2: Disease-Related Issues

Some of the barriers to the use of institutional respite mentioned by the participants were related to the disease itself. Two categories were reflected: trauma of relocation; and the inherent needs of Alzheimer's patients

A. Trauma of relocation

All five caregivers stated that the care-recipients' lives were based on structure and routine and that putting their loved one into respite would significantly disrupt this routine. One husband explained: "routine is very important, that's the potential problem with institutional respite...I'd need to know that she could cope in a respite situation". Another caregiver thought about how her husband would respond if she asked him to go into respite: "if he were away, he'd miss the routine, he wouldn't go for it". In addition, all of the caregivers expressed concern over whether or not their loved one would be able to settle in an institutional environment because it was an unfamiliar place to them. As one caregiver stated, "I've seen their [Sunnyside's] beds and everything like that, I don't know...for sure she's not going to want to be there because it'll be strange to her...I find if I keep her in a routine..."

All seven participants stated that in-home services, rather than institutional services, were a more suitable long-term option for Alzheimer's caregivers. Caregivers gave many reasons as to why they preferred in-home services over institutional, but generally, it was because in-home services were seen as less disruptive to the care-recipient's routine. Several caregivers said that they would worry so much about how the care-recipient was doing in the facility, that they probably would not be able to enjoy themselves, so respite would not be beneficial to them.

One professional confirmed caregivers' preference for in-home services:

With inhome respite, it's easier for them... so there's a pattern established that says it's okay to have someone come in because everything else is the same, but somehow this [institutional respite] isn't okay because I'm changing the location, I'm changing everything...I suspect that that may be a bigger barrier than others.

B. Inherent needs of Alzheimer's Patients

1. Everyday is different

All of the caregivers spoke about Alzheimer's Disease being different from other illnesses in that everyday was different, making it almost impossible to plan for anything, especially long-term respite:

It's almost like Jekyl and Hyde, the stress level is never knowing from one day to the next what's going to happen, you can't say, 'well tomorrow I'll plan this' because you won't be able to do it, you can't plan...it's like a spark plug, today the spark plug is sparking and who knows tomorrow...there's nothing constant really.

Some of the caregivers commented on the fact that having to plan so far in advance for long-term respite just wasn't realistic for people caring for individuals with Alzheimer's Disease; the care recipient's level of functioning, mood, and abilities can be so different from one minute to the next, making it difficult to make arrangements ahead of time.

2. Alzheimer's as a special case

The majority of the participants explained that Alzheimer's patients had different needs from other patients, which served as a barrier because, again, they feared that institutions could not provide for the specific needs of persons with Alzheimer's Disease. The participants brought up the following concerns that would interfere with the use of institutional respite: worry over the care-recipient's safety due to memory loss and the tendency to wander, incontinence and going to the bathroom in strange places and the fear that he or she wouldn't be kept clean, communication difficulties due to the care-recipient having reverted to his or her first language, and worry over how the staff would deal with difficult behaviours, including aggression.

The caregivers also mentioned that their day was "consumed with caregiving", and that it was "a 24 hour a day, seven day a week job", and that they could not imagine putting the care-recipient in a home where they would not receive the same care. One of the professionals explained that caregivers had trouble dealing with the fact that the amount of care they provided at home would not be duplicated in an institution:

> *...and it's true, we can't provide the one on one care that they provide at home and that's a big step for a caregiver, to have their loved one put into respite and let others care for them and not the same way because it's not the 1:1, we can't always be with them...we have the 24 hour care, but it's not the same as them being alone with them.*

Category#3: Service System-Related Issues

The participants had a lot to say in terms of the systemic issues related to the underutilization of respite services. The service system-related issues generally fell into one of the following five categories: availability; accessibility; suitability; satisfaction; and lack of awareness.

A. Availability

All of the participants commented on the inflexibility of institutional respite, particularly that it had to be planned far in advance and that the hours were not flexible. Two of the caregivers had actually tried to use respite in the past, but there was nothing available at the time they needed it. One caregiver shared his unsuccessful attempt at using respite:

> I *actually tried to use respite once, but couldn't work out the semantics...I had the plane tickets and so on and so forth and I needed three days. Well, there was only one home in Waterloo Region that could do that, no, it was the one that was the closest, but they couldn't have her longer than the ten o'clock Monday morning...institutions need to be more flexible and could accept quick decisions on my part.*

The professionals agreed that inflexibility and availability were often a problem, as one professional stated: “given the number of clients with Alzheimer's Disease and the number of respite beds, there is a mismatch for sure...we have certainly put forth the case that we could use more beds”. The other professional reiterated the above sentiments: “people definitely have to book ahead of time, we have bookings up till the end of December now, on and off [the interview took place in mid-June]...you can't get anything at the last minute”.

B. Accessibility

1. Eligibility

The professionals considered the eligibility requirements to be rather straight forward, as one explained:

> *Really the criteria are that they need assistance...when their needs are such that, even with putting all of the services in place, it's still beyond the family's capacity to cope...really the eligibility criteria are pretty broad so there really aren't too many barriers to using that way...people at the very, very early stages might not be eligible for respite...if we see that they [the care-recipient] can be left alone, it's hard to make the case for respite because respite is when the caregiver must be there 24 hours a day...probably the key transition point would be when the family member can't be left alone safely...I mean, once you're eligible, you're eligible, then you can choose how much you want.*

Based on input from caregivers, it appeared that eligibility for respite was not as simple as stated above. Respite was a problem for families in that they felt that services were only available when the care-recipient was "really far gone" and that there were no long-term respite services available for somewhat higher functioning clients.

The caregivers felt that they had to make their situation, meaning the care-recipient's abilities and so on, appear worse than they were in order to get more services. One caregiver, who had been caring for her father with AD as well as her mother with Schizophrenia, stated that her biggest barrier was trying to make her mother eligible for long-term care in order for both her parents to go into respite together.

2. Geography

Some of the caregivers were dissatisfied with the fact that there weren't respite services closer to their homes. One caregiver spoke about his disappointment with the lack of institutional respite programs in Cambridge, Ontario:

> *...for the life of me I couldn't believe that there wasn't something to help people with this disease. It's sad that in a city our size, that with the disease my wife, actually numerous people, have...but to me, why should I have to bring my wife from Cambridge to Sunnyside, there should be something in Cambridge just like there is here, very disappointing. You have to fight, when you talk about our health care, you don't realize until you need specialized care...you can get open heart surgery and whatever, but when it comes to looking for care for dementia patients, like I said, there is more in Cambridge for my dog than for my wife.*

3. Cost

All of the caregivers mentioned the financial burden of caregiving. Several mentioned that they had been "dipping into life savings for years". One caregiver said: "I know there are services available, but they cost money". It appeared that the cost factor may have even been underemphasized due to the caregivers' sense of pride; all of them mentioned financial problems, but when asked if cost was a factor in using services, all of them replied that they were "fine" or "okay". Only one caregiver explicitly mentioned that his pride had gotten in the way of accepting financial help from his son.

4. Navigation difficulties

Caregivers indicated that the process of inquiring about and attaining respite services was an extremely difficult one; they described working through the system as "being lost" or as "having to deal with the whole political garbage". Both professionals supported the notion of a complex system. The CCAC manager explained that her agency's purpose was to act as a facilitator for families:

> *I think a central point of access is helpful because it's a really complex system to try and navigate, I mean it's incredibly complex...for anybody, and I think, if you have a case manager to help you with the linkages, in the beginning...I won't say the system is perfect, but I think the intent of having that central point of access was just that, it's a complex system, it needs to be navigated, and sometimes you need someone along side you to help you navigate...*

One of the potential consequences of a system that is difficult to navigate is confusion around service use; this was certainly evident in the current study. Several of the caregivers did not understand how institutional respite services were separate from long-term care placement, and both professionals commented on how easy it was for caregivers to misunderstand the purpose or process of long-term respite. One professional stated that respite is "something that they [families] have just heard about, but they really don't understand what it means and how it can be beneficial to them".

C. Suitability

1.Lack of diversity

All five caregivers and one professional commented on the inability of institutions to accommodate client diversity, whether it be for age, culture or language, range of activities, level of functioning, or unique family situations. One caregiver was afraid that her mother would be neglected because there would be no staff that could speak her mother's language. Another caregiver had a unique situation in that she was the primary caregiver for her mother with schizophrenia and her father with AD. She explained the difficulties she had had trying to find a facility that would take both her parents together as the two refused to be separated; institutions would say that her father was eligible, but not her mother.

Some of the participants mentioned that institutional respite was not suitable because of the lack of activities for younger Alzheimer's clients. They stated that institutions were for "old, frail people" and that their loved one was too physically active to be placed in an institutional setting. These same caregivers said that they would consider using long-term respite if their loved one could be involved in more "active activities" while staying there.

2. Need for specialized services

Some of the participants stated that caregivers would be more likely to use institutional respite if the programs better catered to the needs of Alzheimer's clients.

One professional stated that an effort was needed to make institutional respite more suitable for AD clients:

> *I think from the Alzheimer's population, it would be great if there was some way of having respite in a unit where there were already good programs for the cognitively impaired client, I think, perhaps, families would be more willing to use if they felt that they [the care-recipients] were going into a specialized unit...*

D. Satisfaction

1. Previous negative experiences

Four of the five caregivers and the two professionals described a progression of service use, which involves families testing less intrusive services, evaluating them, and then potentially trying other services based on the success of the first services. As one caregiver phrased it: "If you swim half way, and it's okay, then I'll go the full distance".

It appeared that families' earlier negative experiences with the system had a significant impact on their later decisions around institutional respite. Three of the five caregivers spoke about past negative experiences with the system and how these experiences had contributed to their being fearful of using services again. Two caregivers spoke about difficulties with and the lack of empathy from CCAC employees, as one explained: "When I started with Community Care Access, I had more than a few bumps...some of it was a bad experience...I was disappointed with some of their employees, very disappointed..."

One caregiver spoke about two incidences of actual respite use wherein her mother was treated poorly. The caregiver stated that one incident had occurred while at an Alzheimer's day program, the other during an overnight stay in a hospital; the latter was described as follows:

> *We had her in the hospital once and she walked out of that hospital that night or that next day bruised like…we even took pictures of her, she had bruises all over her whole body, they tied her into bed, and I don't know, I'm not saying Sunnyside would do this, because this was the hospital and I know the nurses don't have a lot of time…I look at that picture an awful lot and I think to myself if I ever saw my mother go through that again… that was a horror, horror experience…it turned out to be the worst night of her life and our lives because we were scared after that…I mean maybe they'll take her, she'll settle, and I'll have a great weekend, but what is she going to go through?*

2. Lack of choice and control

Some of the caregivers mentioned that they were afraid of losing control once they allowed CCAC and others to be involved in the care of their loved one, and that this had caused them not to use services. One caregiver explained:

> *We were actually a bit fearful of CCAC, I had heard a couple of really bad stories, one was actually from a doctor, and it was just that the control was taken away from us. So when you hear that, and the way it's presented to you, already you get your back up… you don't want to call on the services. You know, it puts you in that state of 'do you really want the help or do you want to try and continue to do it all yourself?' and then that just stresses you out even more because you kind of get into this loop of feeling like you are out of control, and that's not a good place for a person to be because that's when you get sick, you need to know that you're in control of your situation and anything in life…*

E. Lack of awareness

1. Denial

The caregivers all stated that they had gone through a period of denial, and the majority said that this had delayed their looking into services. Four of the five caregivers said that they had never spoken about the disease with their loved one because it was too difficult or for fear of devastating the care-recipient further. All of the caregivers shared that they had formed a habit of "not lying, but stretching the truth" so as not to hurt their loved one, but also as a way of protecting themselves.

One of the professionals explained how denial affects families' decision-making:

> *...families are often in a bit of denial, you don't want to believe that this is happening, and you're very hopeful when that person has a good day...let's not...the last thing you want to do is stigmatize someone with a label, and so sometimes even making those first moves...it's fraught with a lot of emotion, it's very, very difficult for families, so again, perhaps they would do something differently...*

2. Service fragmentation

Both caregivers and professionals spoke about the lack of connectedness between the various service providers, particularly in terms of education about the disease and information about available resources and services. One professional who is employed in Sunnyside's admissions department shared: "So many people are involved and they're relating their story over and over again...I can see how they get missed depending on where they're at...and that's true...on tours I've done, families have said that they never knew respite was available".

The above professional explained how she thought her facility could better serve families:

> *It would be nice if we could actually be the ones to initially meet with families, you know, do the initial assessment and meeting with the families in their homes, and then we'd have a much better idea, and they'd have a much better idea as well of what we're all about, we see right away whether it's a good fit for them...we'd probably be able to do more problem solving or counselling around that as well with that much more involvement...you know, really gain their trust...we are kind of restricted that way...we wait for people to come to us.*

Several of the caregivers mentioned that they had found out about services accidentally, and often on their own initiative. Essentially each caregiver had a different story about how they had found out about Alzheimer's Disease and available services; one was informed by a family doctor, one found out sporadically through interaction with a series of specialists and doctors, one elderly caregiver's son, who lived in British

Columbia, phoned the Waterloo Region CCAC and inquired about services and then informed his father, and two found out by contacting the Alzheimer's Society on their own initiative. One caregiver shared his experience:

> *When I finally said I have to cope with this, it's a long journey, I contacted the Alzheimer's Society, and then found out, almost accidentally, about Community Care Access Centre…At first I was lost, there was nothing publicized about these programs, especially in my community…there were few agencies that would give me answers, I happened to…somebody on a phonecall that I made referred me to X, who was at one time, the administrator of Sunnyside, and that's how I found out about Sunnyside.*

All of the participants emphasized the importance of early education and how having knowledge about the disease early on could have a huge impact on service use. The caregivers spoke about having needed to understand more about the disease, about what to expect, about how the disease affects the individual who has it; they said it would have helped them make better choices around service use.

Chapter Five:

Discussion

It is well known that institutional respite utilization rates for Alzheimer's clients are quite low (Montgomery, 1988), but there has been little research that points to the exact reasons why this is the case. It is important to keep in mind that the decision to use or not use respite services appears to be determined by an interplay of several factors rather than by one factor acting in isolation; families engage in an intricate decision-making process when considering whom they will allow to care for their loved one.

The qualitative data obtained in this paper raise important questions about the sort of things that play into a family's reluctance to seek or use respite, specifically institutional respite. Further, the results of this study identify several policy and research implications that should be investigated in greater depth by other researchers, policy analysts, and program planners so as to improve the quality and utility of institutional respite services for Alzheimer's clients.

Identifying the barriers

The participants in this study identified several items that were perceived by Alzheimer's caregivers to be barriers to the use of institutional respite. The barriers reported in this study fit into one of three classifications; those related to the caregiver, those related to the disease, and those related to the service system.

The most prominent caregiver-related barrier reported in this study was undoubtedly the feeling of guilt; this is consistent with the majority of the research on barriers. One reason caregivers felt guilty is that they believed that they were abandoning their loved one if they placed him or her, even temporarily, in an institution. Smyer and Chang (1999) similarly found that, in the antecedent phase, when caregivers are contemplating respite use, they experience a strong sense of guilt when thinking about leaving their loved one in a facility.

Grasel (1997) found guilt related to feelings of abandonment to be closely related to cultural attitudes about family responsibility. Culture as well as family values played a large part in the present study as well. Caregivers felt that because they were related to the care-recipient, they had an obligation to provide care. It was interesting that several caregivers pointed out that although the caregiver role was something that they had not anticipated, and admitted that it had caused them a great deal of stress, they also expressed that it was taken on willingly and was "just something that you do [sic] ".

Responsibility and obligation to care has been said to stem from the caregiver's sense of reciprocity of care; that is the feeling that because the parent had once taken good care of them, it was now their turn to return the care to the parents (Dupuis et al., 2004). Caregivers in this study mentioned that their parent had taken care of them and that they saw it as their responsibility to care for them in a similar way. Interestingly, the spousal caregivers also identified with the concept of reciprocity in care. Caregivers believed that their husband or wife would have done the same for them if the roles had been reversed, therefore, they had no trouble providing such a high level of care.

Caregivers stated that some of their guilt had resulted from input from other family members; decisions around care and service use was a major source of tension between primary caregivers and their families. Previous research shows that conflict is quite common in families with ill elderly, especially when the elderly person has dementia (Dupuis et al., 2004). In this study, it appeared that family conflict worked to further isolate primary caregivers, reinforcing their decision to provide care on their own. Caregivers decision to provide care without formal or informal help appeared to be partially related to resentment and mistrust in others, including their own family members.

Previous research has stated that caregivers who have additional family supports and small amounts of burden are less likely to use formal services, including institutional respite (Dupuis et al., 2004). This study found the opposite to be the case in that the caregivers were providing care with almost no assistance from family and had experienced extreme amounts of burden, but were still reluctant to use institutional respite services.

Another reason caregivers felt guilty had to do with long-term care facilities themselves and the negative stigma attached to them along with the fact that caregivers knew that the care-recipient did not want to be put in a home. Institutions were thought to be homes for very old, frail people and caregivers did not feel that such an environment was suited for their loved one. Scharlach and Frenzel (1986) found that patients did not like being around people whom they perceived had more severe disabilities than their own. The findings here reflected the same thinking in that caregivers reported that the care-recipient was “not there yet”, meaning that they were not as incapacitated as residents in long-term care facilities. Some caregivers here reported that although their loved one had dementia, his or her awareness as well as physical abilities were very much intact, and therefore it was too early to consider institutional respite.

Grasel (1997) found the initiation of temporary institutional respite to be absolutely critical in that it had to be "before the family caregiving breaks down, but not too early that it demoralizes the care-recipient". The caregivers in this study appeared to care more about not demoralizing the care-recipient than about their own physical and emotional well-being, some even stating that their biggest barrier to institutional respite use was knowing that the care-recipient would be ashamed or embarrassed about being in a long-term care facility.

A major concern reported by the participants of this study was guilt as it related to the fear of inadequate care. This was a concern mentioned repeatedly in the literature as well (Dupuis et al., 2004; Grasel, 1997; Rudin, 1994). Caregivers were extremely worried, whether from past negative experiences, from stories they had heard from others, or just from the stigma that accompanied institutions, about the amount and quality of care their loved one would receive in an institutional environment. Further, the professional participants found it difficult to assure caregivers that temporarily handing over care could be beneficial, knowing full well that the care in institutions could not possibly match what the caregivers were doing at home.

The caregivers also spoke about potential guilt they would feel if their loved one were harmed in any way while in an institution. Caregivers stated that they could never forgive themselves if something did happen, therefore it was easier to deal with their own stress and burden rather than taking the chance that the care-recipient could be physically or emotionally hurt.

Following guilt, the second most significant caregiver-related barrier was the caregiver/care-recipient relationship. Caregivers had trouble “letting go” of their loved one and handing over care to someone who had no emotional history with the care-recipient. It was common for caregivers to view institutional respite use as the first step in the separation between themselves and the care-recipient. Although there is little research in this area, some studies have found a deterioration of the relationship between the caregiver and the care-recipient following institutional respite use (Flint, 1995).

Institutional respite was seen as having more of an adverse effect than day or in-home respite on the caregiver/care-recipient bond because the separation was for a significantly longer period of time. Little research has been done which considers the impact of varying lengths of respite use (Adler, 1992), but as this study suggests, the length of separation between the caregiver and care-recipient is something that needs to be considered when assessing the differences between the three major types of respite and the reasons behind why institutional respite is rarely used.

The second types of barriers reported were those related to Alzheimer’s Disease itself. Alzheimer’s Disease was seen as being very different from other illnesses mainly due to the gradual loss of memory and cognitive impairment, along with the need for an incredible amount of structure in the family’s routine. Caregivers reported that one of the major reasons they would not put their loved one into institutional respite was for fear that the disruption in routine would cause the care-recipient psychological and/or emotional damage. Caregiver translocation worries have been reported in a number of studies (Brody et al., 1989; Flint, 1995; Grasel, 1997; Montgomery et al., 2002; Smyer & Chang, 1999) and is definitely something that needs to be taken seriously in future research.

Some caregivers thought that because of the way the disease had affected the care-recipient, staff would have difficulty managing their relative which deterred them from accessing the service at all. It appeared that caregivers were making a connection between a care-recipient who was perceived as having a high need for care and the fear of inadequate care. Caregivers feared that the staff in institutions could not adequately deal with the behaviours and care needs of a patient with AD, and research shows that this fear around the quality of care in institutions is not unrealistic (Scharlach and Frenzel, 1996)

Fear of actual physical abuse was mentioned by only some of the participants, but the fear of emotional abuse and/or neglect was mentioned by all of the participants. Although elder abuse was beyond the scope of this research, it is something that needs to be considered in future research on respite underutilization as well as in research designed to evaluate the quality of care in long-term care facilities in general.

The third types of barriers identified in this study were those related to problems within the service system. Caregivers and professionals both agreed that there was a mismatch between the number of persons with Alzheimer's Disease and the number of respite beds in institutions. The shortage of beds has led to respite not being available when caregivers need it and to having to plan several months in advance if they want a bed. Planning in advance was not considered an appropriate option for caregivers of

Alzheimer's patients due to the fact that everyday is perceived to be different, therefore planning anything in advance is simply unrealistic to them.

The majority of recent literature points to a need for more respite beds as well as increased system flexibility so as to better accommodate families with transitional needs, such as those caring for loved ones with dementia. The MAREP study, the most recent research on dementia caregivers in Ontario, did not include information on caregiver's perceptions of institutional respite. It is possible that institutional respite fell under another category such as "other support services" or that caregivers never mentioned it (Smale & Dupuis, 2004). Nevertheless, it was surprising that a study wherein dementia caregivers identified their needs, institutional respite appeared to be completely absent.

Another system barrier was the lack of accessibility stemming from unrealistic eligibility criteria, lack of services in the caregivers' regions, service costs, and system navigation difficulties. These issues of accessibility support previous research which identifies system complexity and difficulty in navigating the system to be related to misunderstandings around eligibility and costs (Dupuis et al., 2004). This study along with previous studies clearly demonstrate that caregivers find health and social systems to be incredibly complex, so much so that the complexity has become a significant factor in the disuse of services (Smale & Dupuis, 2004; Smyer & Chang, 1999).

This study found that caregivers generally understood that respite was meant to give them a break, however, they did not understand how respite worked and how it could benefit them. Probably the biggest misunderstanding was the belief that temporary respite was a precursor to long-term placement or that qualifying for respite meant that the care-recipient was automatically put on the long-term care wait list. Other research has similarly found caregivers to hesitate using institutional respite for fear that it will lead to premature institutional admission (Brody et al., 1989).

Eligibility and cost, apart from system complexity, could be considered issues in themselves. The present study as well as past literature (Montgomery et al., 2002; Rudin, 1994) found that caregivers viewed eligibility criteria not only difficult to understand, but difficult to access services within. Rudin (1994) specifically found that the behavioural and functional eligibility criteria of institutional respite often precluded many caregivers from using it. Interestingly, caregivers and professionals in this study differed in their views of eligibility criteria with the latter believing that eligibility criteria were straight forward and rather lenient. In terms of service costs, a lack of financial resources were an issue for caregivers in the present study. The literature on service affordability is fairly definitive, simply stating that respite is rarely available to those who cannot manage to pay for it (Smyer & Chang, 1999).

Another system barrier was that institutional respite was considered, in some ways, to be unsuitable for both caregivers and care-recipients. Suitability issues identified were lack of diversity and the need for specialized services. Lack of diversity was apparent in the areas of age, patient functional abilities, culture and language, and unique family situations and the need for specialized services was connected to the lack of Alzheimer's-specific respite in institutions. Suitability is an issue that does not appear to have been explicitly mentioned in any of the previous literature, although previous research does emphasize the need for services that reflect patients of different ethnic and cultural backgrounds (Kosloski, Schaefer, Allwardt, Montgomery, & Karner, 2002).

Caregivers in this study expressed an overall dissatisfaction with the respite system. Several of them mentioned previous negative experiences with CCAC and other forms of respite and a number of them expressed concern over the lack of control they felt they had as a result of accessing the system. This phenomenon is somewhat related to other research that shows that caregivers are more likely to use respite if they feel they have the ability to exercise some degree of choice as well as the right to retain some control over care (Feinberg & Whitlatch, 1998).

The final system-related barrier was a lack of service awareness, resulting mainly from caregiver denial and service fragmentation. Caregiver denial is apparent in the majority of past literature, and is something that caregivers in this study said had caused them to avoid looking into services. Service fragmentation could be considered a more macro issue in that it addresses changes that need to be made to the system. Despite the implementation of CCAC's across Ontario, caregivers are still 'falling through the cracks'; they are not finding out about services, and if they are, it is often accidentally and at the wrong time, they are not receiving enough information about the disease, and they are not being approached by long-term care staff so as to accurately assess their needs and to aid in the development of a trusting relationship. Recent research by Dupuis et al. (2004) supports the idea that service fragmentation is a serious issue for dementia caregivers and that Community Care Access Centres have done little to remedy this problem.

There appears to be confusion around whose responsibility it is to educate caregivers about the disease and to inform them of the various service options. Caregivers reported finding out accidentally and/or sporadically about respite services. Previous research has also found that caregivers feel undereducated and unaware due to insufficient information from physicians and service professionals (Fortinsky & Hathaway, 1990).

Limitations of the Study

One limitation of this study was the small number of respondents. However, the strength of qualitative research is attained through detailed analysis of recurring concepts and themes which stem from in depth examination of a small number of participants' experiences, interactions, and perceptions (Patton, 1987).

A second limitation was that the sample was not randomly selected. It is possible that some bias was involved in Sunnyside's coordinator approaching participants whom she felt were appropriate interviewees. Nevertheless, some of the participants expressed negative views about Sunnyside, which suggests diversity in the participant selection process.

A third limitation was that the sample did not include care-recipients. This population was considered too vulnerable to participate in this particular circumstance, however, the extent to which persons with Alzheimer's Disease could offer valuable insight into the issue of service underutilization should not be dismissed.

Despite the above limitations, studying key people, primarily caregivers, but also service professionals who assist caregivers on a daily basis, has led to a more comprehensive understanding of the issues relevant to the underutilization of respite services. Presently, there is very little known about the barriers to the use of institutional respite specifically for the Alzheimer's population, therefore this study could be considered a starting point for future Alzheimer's policy and program-related research.

Institutional respite redirection

Many of the barriers to institutional respite identified in this study have been supported by previous research. However, this study has gone into greater detail than other studies and has also identified additional barriers that have not been addressed in past literature. Considering that more recent programs and policies have been aimed at supporting families in their caregiving efforts, caregiver input surrounding the barriers to the use of these services is absolutely critical.

Institutional respite is an area of particular importance as it is highly underutilized, and therefore more susceptible to funding cuts, and subsequently, decreases in the amount and quality of services. Policy makers need to be made aware of how institutional respite operates in the caregiving situation, its function, and the conditions that lead to optimal use before concluding that it is an unneeded service (Berry et al., 1991).

Based on input from the present study as well as previous studies, the following suggestions for improving the design and delivery of institutional respite will be made:

- That institutional respite be explained by the physician, upon diagnosis, and periodically throughout the progression of the disease, especially when the caregivers are most likely to use it.

- Consideration of a provincial or municipal booklet or package of resources to be given to caregivers upon diagnosis of the disease which would include disease education, service and support information, contact numbers, and so on.

- That institutional respite be offered as part of a multi-service system, wherein it is accompanied by careful assessment, caregiver education, consistent case management, and skilled counselling (Brody et al., 1989).
- That physicians, case managers, long-term care staff, counsellors, or whomever is explaining institutional respite, take special care to address/discuss and minimize caregiver guilt.
- That facilities include special care units that cater to the specialized needs of Alzheimer's patients; a unit that is safe and secure, but that still maintains a home-like environment.
- That more beds be placed in institutions so as to increase availability and flexibility for caregivers, and to decrease the length of time caregivers need to book in advance.
- That institutions accommodate diversity in functioning levels, culture and ethnic background, and unique family situations, and making sure that eligibility criteria reflect this as well.
- That the application for temporary respite and permanent long-term placement be completely separate to avoid further confusing caregivers and to make it clear that they are not the same thing.
- That caregivers be involved in the entire respite process so that they feel assured that care will be as much like the care-recipient's home environment as possible; required memos and care directives, scheduled telephone conversations with staff if desired, staff-caregiver communication journal, and so on.
- Presently CCAC's facilitate all institutional respite services; the system does not allow institution representatives to approach families themselves. The recommendation, in this case, would be to allow representatives from long-term care facilities to approach families on their own initiative to allow for a better assessment of fit between the potential patient and the facility, to better assess care needs, and to help build a better relationship of trust and combined concern for the care-recipient.

Alternative service considerations

In addition to changing the institutional respite system, alternative service options should also be considered so as to accommodate families who remain reluctant to its use. Alternatives should take into consideration the fact that families take on a considerable amount of care responsibility and in doing that, are saving the government significant amounts of money. Alternatives should also take into consideration that families want to retain as much choice and control as possible.

One alternative to formal respite intervention is family compensation programs, which include a direct or indirect financial reimbursement to family caregivers (Dupuis et al., 2004). Indirect programs usually involve a tax relief or credit for supports or services after they have already been purchased by the caregiver. One problem with this is that many caregivers do not have the money to purchase services upfront, and a second problem is that if the province exceeds its special needs budget before the end of the fiscal year, it may decide to not pay until the next fiscal year or to not pay at all (Dupuis et al., 2004). A third problem with indirect payment programs is that caregivers are still at the mercy of the system; the system dictates which services they can access based on which services they are willing to reimburse.

One way of giving back choice and control to families is to implement a direct pay program wherein caregivers are given a financial payment to purchase the services and supports that they feel their family member needs (Feinberg & Whitlatch, 1998). These types of programs began as part of the independent living movement and were intended to empower people with disabilities by allowing them to make their own decisions related to their individual care needs (Dupuis et al., 2004). Studies show that people's needs are better met by allowing them to create their own mixes of formal and informal services (Lawton et al., 1989b), therefore direct pay programs may be an alternative for Alzheimer's caregivers.

Direct payment programs would also work well in that they account for the transitional nature of the disease; families with transitional needs require a great deal of flexibility in services and are likely to require a continuum of services as the disease progresses (Montgomery, 1995). Direct pay programs allow families to choose the services they need at different stages of the disease.

Direct pay programs still do not accommodate caregivers who wish to provide all of the care themselves. One way of addressing this phenomenon is to provide direct financial compensation for caregivers. Almost all industrialized countries have recognized, to some degree, the need for direct financial assistance to family members who care for disabled or dependent members (Linsk et al., 1995). Scandinavian countries like Norway and Sweden have done better at implementing such programs as they have been considered an equality and equity- enhancing alternative for, primarily, women caregivers as well as a substitute for scarce resources (Dupuis et al., 2004).

Canada, on the other hand, has viewed caregiver compensation programs as a potential way to save government dollars (Dupuis et al., 2004). There are only a few caregiver compensation programs in Canada and only one program, the Home Life Support program in Nova Scotia, has undergone any type of analysis (Dupuis et al., 2004), therefore it will probably be some time before caregiver compensation is considered a viable alternative to formal services.

One last alternative to institutional respite would be to provide long-term respite in peoples' homes or at least in a more home-like environment; both of these would minimize the issues of institutional stigmatization and trauma of relocation. Unfortunately, these programs are scarce, but there are a few that exist in Ontario. One such program is the CCAC Alzheimer's Respite Program, which provides up to fourteen days of in-home respite. As was previously stated, this program is unique to the CCAC in Kitchener-Waterloo and was accomplished with the use of a small, finite amount of funding that the organization had set aside for Alzheimer's services. This program serves approximately sixty families, and has a long wait list.

Wesway is another program that serves Alzheimer's clients in a home-like environment, although it currently provides only weekend assistance. Wesway is a program that was initiated in Thunder Bay, Ontario in partnership with the St. Joseph's Care Group. The program does not receive public money and survives off of funding from churches and donations. Wesway also has a long wait list, years in fact, which could be seen as a reflection of the degree to which this type of service is both appropriate for and appreciated by the Alzheimer's population.

Implications for future research

Several implications for future research have been presented throughout the paper, therefore a brief conclusion will be presented here. The data reported in this research demonstrate that Alzheimer's caregivers infrequent use of institutional respite is far more complicated than simply assessing perceived need versus available services. There has been a tendency for policy and program planners to evaluate institutional respite exclusively on the basis of whether it reduces caregiver burden and delays institutionalization, without considering how caregivers manoeuvre their way through the system throughout the progression of the disease. In order to make informed decisions around service evaluation and modification, planners of respite services need to be cognizant of the varying needs of Alzheimer's caregivers, what types of respite should be offered when, the characteristics of potential users, and how institutional respite affects other formal and informal services (Lawton et al., 1989b).

It is imperative that policy analysts, program planners, and professionals in the field do not assume they know what caregivers need (Novak & Guest, 1989); this information must come from caregivers themselves (Dupuis et al., 2004). The qualitative approach taken in this study attempted to uncover the barriers to the use of respite from the perspectives of caregivers themselves. The inclusion of the professional participants was to provide information on service-related issues as well as to attain extra input from persons who were in contact with caregivers on a daily basis. The inclusion of the professional participants proved to be useful in that it showed that the perceptions of professionals sometimes differed from those of the caregivers.

Caregiver perception is extremely critical in any examination of service utilization (Rudin, 1994). The present study found that the barriers to institutional respite were intricately connected to caregiver's perceptions of guilt and responsibility, the breaking of the caregiver/care-recipient bond, the nature of institutions, the quality of care, and so on.

It should be noted that the perceptions in this study came from caregivers who were all utilizers of formal services. There is a need for research to attempt to access more isolated caregivers who are not users of formal services as they may have different perceptions than caregivers who do use formal services (Rudin, 1994).

As previously noted, this study did not control for variables such as gender, race, age, ethnic origin, or relationship of the caregiver to the care-recipient. Comparison studies are needed to examine the possible variations in formal service utilization patterns of the different caregiver demographics.

Finally, future studies need to be aware that caregivers of persons with Alzheimer's Disease are not necessarily the same as other caregivers, including other dementia caregivers, and therefore have different issues and different needs. It is also important to consider that institutional respite is not the same as day and in-home respite; institutional respite comes with its own set of challenges and barriers that are separate from those of the other two forms. There has been a tendency for research to inappropriately group items or persons together, but if the purpose of research is to attain as accurate data as possible, then special caution needs to be taken in this area.

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Table 1

Summary of Categories and Properties

Caregiver-Related Issues

A. Sole responsibility

B. Feelings of Guilt
1. Abandonment
2. Going against care-recipient's wishes about institutionalization
3. Fear of inadequate care

C. Caregiver/Care-Recipient Bond
1. Trouble letting go over time
2. Emotional history

Disease-Related Issues

A. Trauma of Relocation

B. Inherent Needs of Alzheimer's Patients
1. Everyday is different
2. Alzheimer's as a special case

Service System-Related Issues

A. Availability

B. Accessibility
1. Eligibility
2. Geography
3. Cost
4. Navigation difficulties

C. Suitability
1. Lack of diversity
2. Need for specialized services

D. Satisfaction
1. Previous negative experiences
2. Lack of choice and control

E. Lack of Awareness
1. Denial
2. Service fragmentation

APPENDIX A

CONSENT FORM

I agree to participate in a research study whereby the purpose is to uncover the reasons why persons with Alzheimer's Disease and their caregivers often do not use long-term respite offered through long term care facilities. I understand that permission will be asked (below) to participate in an interview that will last between 1 and 1 ½ hours (90 minutes) and that I will receive $30 remuneration upon completion of this interview. Permission to be re-interviewed/re-contacted if further information is needed by the interviewer will also be asked, and if I agree, I understand that no additional remuneration will be given. I understand that the principal researcher is Tara Berthin, who is conducting research in her capacity as a graduate student at McMaster University located in Hamilton, Ontario; Ms. Berthin will be supervised by McMaster faculty member Jim Gladstone.

I agree to take part in this research under the following conditions:

a. My participation in this research is completely voluntary, and I can, at any time, choose to discontinue my involvement.

b. I may refuse to answer any question at any time.

c. If I agree to be re-contacted, I may change my mind at a later time and refuse to be contacted.

d. My name will not be recorded on the interview form nor the tape recorder, and this consent form will be separated from the interviewer form so that my identity will remain anonymous.

e. No one, outside of those aiding the researcher, will be told that I have participated in this research study.

f. My name and address will be kept by the principal researcher only if a) I agree to be re-contacted and/or b) I would like a summary of the findings sent to me after the research study is completed. Once I have been re-contacted and/or sent a summary of the research findings, any records containing my name and address will be destroyed.

________________________________ ____________________

Participant Signature Date

____

I agree to be re-contacted if necessary

________________________________ ____________________

I do not wish to be re-contacted Date

APPENDIX B

LETTER OF INFORMATION

The purpose of this research is to explore the barriers to the use of long-term institutional respite for persons with Alzheimer's Disease (AD). The research will conducted by Tara Berthin as a part of her master's thesis and will be supervised by McMaster University professor, Dr. Jim Gladstone. Your participation in this research will be kept confidential. Every attempt will be taken to respect your privacy and no identifying information will be included in any reports generated from this study, and all information that you provide will be kept in a locked filing cabinet in a locked office at my place of residence. You maintain the right to withdraw your participation from the research at any time. If you choose to withdraw, all information you have provided will be either returned to you or destroyed.

In participating in this study, you will be asked to participate in a one-on-one, unstructured interview lasting between 1 and 1 ½ hours, which will concentrate on uncovering the depth of your subjective experiences in relation to AD and the use of respite services. You will receive $30 remuneration upon completion of the interview. The interview session will be tape recorded and later transcribed. It is intended that the interviews be conducted at Sunnyside Home, but you may choose a meeting place that is more comfortable and/or convenient for you.

You will receive a written report of the findings of this research. This project has been reviewed and cleared by the McMaster Research Ethics Board as well as by Sunnyside Home's Research Ethics Committee.

Should you have any questions about your participation in this study, you may address them to myself or the McMaster Ethics Board (see information below) or the Ethics Board at Sunnyside Home.

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APPENDIX C

CAREGIVER INTERVIEW GUIDE

i. **What can you tell me about stress and how it relates to being a caregiver for someone with AD?**

- How much time do you spend with…?
- What kinds of things do you do together?
- Do either of you manage to get any time alone, how often and what does it look like?
- Can you think of times when you have been able to have time alone? How was that possible?
- What kinds of things do you do to reduce the stress of caring for your loved one?

ii. **What does the word 'respite' mean to you?**

- Other people have defined/described 'respite' as…, what do you think about when I say the word 'respite'?
- There are different kinds of respite, long-term and short-term, in-home or out-of-home, what is your understanding of respite in connection to the different types?
- What things come to mind as we are talking about respite?
- In what ways has respite been explained to you, if ever?

iii. **Have you ever spoken to your…about respite?**

- If you've never spoken about respite, why do you think that is?
- What did your…say about respite?
- How do you feel about respite?
- How do you think your…feels/would feel about respite?
- What are views or attitudes towards respite?

iv. **In thinking back to the different kinds of respite services, which ones do you think would be beneficial to you?**

- What sorts of things would lead to you using…over…? (costs, eligibility, etc.)
- What respite services are you aware of in your community?
- Which ones do you think your…would be open to using and why?

v. **Describe the fit or non-fit between AD and respite services**

- How has AD affected you? Impacted your family?
- Which services in the community match/don't match your needs?
- What kinds of services do you wish were available to you?
- What kind of services would help you better deal with the difficulties you face on an everyday basis?

vi. **How could respite services better accommodate families dealing with AD?**

- What changes, if any, would you make to how services are offered?
- What changes, if any, would you make to who services are available to?
- What changes, if any, would you make to how services are provided?

APPENDIX D

STAFF INTERVIEW GUIDE

i. **What do you think the word 'respite' means to families and do they everyday difficulties of AD?**

ii. **What changes would you make to the current respite system?**
- What changes, if any, would you make to the way we introduce/present/explain respite to families?

iii. **understand its purpose or what it's about?**

iv. **What is the process/what avenues do people take when they want to use respite?**

v. **In thinking of the different kinds of respite services, which ones do you think are beneficial to persons dealing with AD?**
- What sorts of things would lead families to use…over…?
- What respite services are they most aware of in the community?
- Which ones do you think families are open to using and why?

vi. **Describe the fit or non-fit between AD and respite services**
- Which services in the community match/don't match their needs?
- What kinds of services do they wish were available to them? What kinds of things do they inquire about?

- **How could respite services better accommodate families dealing with the** What changes, if any, would you make to who services are available to?
- What changes, if any, would you make to how services are provided or delivered?

vii. **In summary, what do you think are the main barriers to the use of long-term respite in institutional settings?**

viii. **Is there anything else you would like to add that wasn't touched on during the interview?**