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Respite Care: Its meaning to informal caregivers of clients  
with Alzheimer's and Related Dementias

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### Abstract

Alzheimer's disease and related dementias (ADRD) represent a growing trend in the aging population. Many of those affected are managed at home by loved ones who become informal caregivers and who eventually need a mental break (Alzheimer Society of Canada, 2006). Using a qualitative approach, the purpose of this study was to define the meaning of respite from the perspective of affected caregivers and to explore what contributes to the decision to use or not use existing respite resources. . In depth interviews were held with 12 caregivers from rural Nova Scotia who provided care for their loved ones with ADRD for a period of at least six months. Two clear themes emerged from the data: surrendering and freedom. Knowledge was a third theme identified that contributed indirectly to the concept of respite. Existing support systems, caregiver continuity, flexibility, structure, finances, and individuality were identified as having a role in whether respite services were accessed or not. This study concurs with recent research that respite be viewed as an outcome and services to address these outcomes should be streamlined and individualized.

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The Canadian population is aging (Annual Demographic Statistics, 2005) and with it one can logically expect an increased rate of chronic health care problems and a concurrent demand for both home care services and informal care-giving services. Alzheimer's disease and related dementias afflict a steadily growing population of people in this country and abroad (Alzheimer Society of Canada, 2006). Alzheimer's is the most common form of dementia accounting for 64 per cent of all dementias in Canada (Alzheimer Society of Canada). The need for 24 hour care and supervision will ultimately be provided by family members. Most clients with ADRD are looked after at home by loved ones who provide informal care (Ebersole, Hess & Luggen, 2004; Eliopoulos, 2001).

Caring for a loved one with ADRD is well documented to be challenging, stressful and can wreak havoc on caregivers' health (Hirschfeld, 2003; Patterson & Grant, 2003; Rosenheimer & Francis, 1992). Obviously this becomes a concern for the healthcare system and necessitates the need for supportive services. These services can come in the form of assistance with activities of daily living for the client, opportunities to have discussions with other caregivers in similar roles, access to medical and health educative information and respite services (Braus, 1998; Chappell, Reid, & Dow, 2001; Hirschfeld, 2003).

Purpose of the study

The intention in this project was to study a representative group (caregivers of loved ones with ADRD) using a qualitative approach to define the meaning of respite from their perspective, and to explore what contributes to the decision to use or not use existing public or private respite services. Findings may contribute to a better understanding of affected caregivers experience

with respite and can help inform practice.

### Review of the literature

Research located on caregivers for people with ADRD mainly focuses on caregiver burden and associated stress (Koopmanschap, van Exel, van den Bos, van den Berg, & Brouwer, 2004). Few studies focus on perceptions of this defined group of caregivers regarding what respite means to them. Farran (2001) discovered that respite care investigations were the fewest in number.

Respite is conceptually defined as a break or period of rest for the care-giver (Chappell et al., 2001). Often described in terms of tasks or services, paid caregivers will come into the home to provide meals, personal care, household chores and supervision to allow the care-giver time away. Other forms of respite include sending the client to a long term care respite bed for a period of time, or to Adult Day Care where care and supervision is given (Chappell et al.; Lassey & Lassey, 2001). However, we need to define the term from the perspective of this select group to validate the above definitions.

Alzheimer's disease is a progressive degenerative disease of the brain that impacts day to day functions and abilities (Alzheimer Society of Canada). It eventually affects thought processes, judgment, and physical abilities to a point demanding caregiver intervention (Alzheimer Society of Canada, 2006). A review of the literature by Chappell and Penning (1996) shows the research has been silent on whether those caring for loved ones with ADRD (as a select group) would define respite in the same way other caregivers would. Questions arise whether this group of caregivers would need more respite or different types of respite. What is evident, is that respite is an underutilized service and caregivers' who do not use outside resources surprisingly have fewer informal supports, are more emotionally strained, and have

more functionally impaired care receivers (Biegel, Bass, Schulz, & Morycz, 1993). Those with progressive ADRD become more functionally impaired. All of this supports the need for further investigations into how respite is perceived by caregivers of those with ADRD.

Chappell, et al. (2001) conducted an extensive study through in-depth interviews and focus groups, on the meaning of respite as determined from the perspective of informal care-givers. The caregivers in the study provided care to loved ones with various mental and or physical conditions. Chappell's study involved interviewing caregivers using random sampling. The caregivers in this study (using large numbers), managed loved ones with a variety of chronic conditions. Findings suggested that those who care for loved ones with more chronic conditions and those caregivers with increased age look more to external sources for respite services. The researchers categorized themes into two groups: internal respite and external respite. Internal respite more often involved getting a break while remaining at home, while external respite was largely defined as getting away for a specified time period. Interestingly the authors noted that the more chronic the client condition, the more likely the care-giver described respite in terms of external terms. Due to the increasing complexity of care for clients with ADRD this finding may impact on the type of respite needed for their care-givers, but further study is warranted to validate this, beginning with an exploration of care-giver perceptions. Findings suggest policymakers and service providers redefine respite (having a break) as an outcome rather than as a service (Chappell et al., & Koopmanschap et al., 2004).

Koopmanschap, et. al., (2004), found several variables associated with preferences for support and respite, but the largest determinant discovered was the subjective burden of care-giving, making it very individualistic. They found associations between caregivers' preferences, characteristics of the caregiver, the care recipient, and the caregiving situation helped to identify

the most urgent groups. Their study suggests a need to compare existing respite programs with identified needs and ensuring service provided is cost effective.

Much has been written about the effects of 24 hour care-giving on the health of those providing that care. For example, conducting literature reviews, Dunkin and Anderson-Hanley (1998) and Patterson and Grant (2003), discovered that care-giving can be associated with many negative emotional and physical outcomes that affect well being but they also agree that still other care-givers discuss positive experiences. Their findings suggest the necessity of taking the needs of caregivers providing care to dementia clients into account when providing assessments and interventions. This strengthens the position for the necessity to go directly to the source to determine what respite means to this group of caregivers. Without an understanding of the definition from their perspective, we may be failing a valued group of people who provide an irreplaceable service to their loved ones.

Winslow (2003) in studying family caregivers' of clients with ADRD experience with community services, showed both benefits and barriers to the services. Many caregivers reported a feeling of renewal, increased knowledge, and a sense of community developing as a result of service usage including respite services. Yet barriers to service were identified as caregiver resistance, reluctance of the caregiver, difficulties for the caregiver, and concerns over quality and finances. Thus it remains imperative to direct our interventions for caregivers in such a way as to ensure services offered are useful. Again, it is important to hear from the caregivers of clients with ADRD, regarding what respite is and what help would be most appropriate.

Other research has focused on what aids the informal caregiver to continue providing care as opposed to admitting them to nursing homes. Hirschfeld (2003) explored the factors influencing a family caregiver continuing to provide care for an older person with senile brain disease at

home as opposed to institutionalizing them. Her findings found mutuality to be the largest predictor and she discussed mutuality in terms of four different groups. Some members of the group with low mutuality benefited from outside intervention in the form of respite depending on the quality and extent of services. Management ability, morale and tension were variables that influenced the caregiver's outcome. Findings support the necessity for preventive, maintenance and curative services to be provided at home, keeping in mind participants identified quality and extent as important factors. This supports the need to explore further what is meant by quality in terms of respite. She goes on to discuss respite in terms of granny-sitters, day cares with transportation provided, live in non-professional low cost help or time limited respite beds in care facilities. In terms of caregiver guilt, hopelessness, resentment and helplessness, she asserts support is necessary in the form of support groups, non-judgmental listeners, and in home professional nurse consultants.

It is evident from the literature that respite is an underutilized service for many reasons. In a recent report released by the Department of Health Continuing Care Branch (2005) the need for more flexible respite care was identified by the public as an area in need of change. Chappell et al. (2001) asserts many caregivers do not define respite in relation to a service provision thus this may contribute to the reluctance to look for or accept these outside services. Many suggestions abound: service is too costly, service too difficult to access, lack of consistency in securing the same replacement caregiver, formal caregivers having vast differences in approaches to care, unaware of service being available, and feelings of guilt in taking time off to name a few (Chappell et. al, 2001; Hayes, 1999; Morgan, Semchuk, Stewart, D'Arcy, 2002; Winslow, 2003). Yet, studies confirm that primary caregivers will cite respite as one of the most useful and necessary services (Miller, 2002). Although many caregivers will report positive experiences, the

reality remains that caring for a loved one with ADRD is a challenging, stressful, all encompassing, and exhausting task. Caregivers can benefit from supportive services and barriers to program use must be identified on an ongoing basis and addressed (Hayes, 1999).

Current thinking views respite as an outcome rather than as a service (Anderson & Parent, 2006; Chappell et al., 2001; Meredith & Meridith, 2003). Consideration of caregiver experiences is paramount to effective programming contributing to successful outcomes. Listening to the voice of those who know (caregivers) should impact future program development.

## Methods

### *Participant selection*

Participants were chosen using purposive sampling. Inclusion criteria included: ability to speak English; have provided 24 hour care for their loved one with ADRD for at least six months; male or female; receiving no remuneration for service; and may work outside the home. The initial intent was to recruit participants through the Department of Health (DOH), Continuing Care Services Branch with the help of the Director and through three Community Alzheimer's Support Groups with the help of group facilitators. Securing participants through the DOH was not possible due to time constraints and a lengthy process of approval from the DOH provincial office in Halifax, Nova Scotia.

Facilitators of three Community support group for caregivers of loved ones with ADRD were approached and asked to participate. With their cooperation, potential candidates were identified and provided a short description of the project by the facilitator. Those who were interested in hearing more about the project were then contacted by the researcher at a later date, given more information and invited to participate. Additionally, the Alzheimer's Society of Cape Breton held a Senior's Expo at which pamphlets outlining the study were handed out along with

the researchers contact information. All were reassured participation was on a strictly voluntary basis and they would have the opportunity to ask questions or withdraw at any time. Informed consents were reviewed with participants and signed prior to engaging in a dialogue with them.

Twelve participants were selected and interviewed. Interviewing continued until the data were saturated (repetitive). Data was categorized, coded, analyzed and themes developed. All caregivers were female; the majority between the ages of 45-65 years. Nine participants were married or living common law and had the help of their partner; 3 also had other dependants under their care; 2 provided care for their husband and 10 for their mothers. For 7 of the participants yearly household income was under \$40,000; 7 of the participants worked outside of the home while caring for their loved one. The majority (n=8) had a high school education. Care was provided for the loved ones for a period of 1 to 7 years. Of the 12 participants, 8 had already placed their loved ones in LTC facilities (4 of whom have now passed away) and 2 were actively considering this move.

#### *Design and procedure*

Before embarking on this research, ethics approval was received from the Athabasca University Research Ethics Board. Following full ethics approval, an addendum was sought and permission received to attend the Cape Breton Seniors Expo for the purpose of securing additional participants.

Initially, a small set of demographic data was collected to provide a general description of participating caregivers. In depth open ended interviews were held with participants individually at an agreed upon time and place and then transcribed verbatim. The interviews were audio-taped to ensure accuracy of data collected, while taking into consideration participant comfort. An average interview took about one and a half hours. Initially each interview was guided by broad

questions with individualized questions arising out of data generated. The following questions/statements were some of the typical questions asked of participants:

- 1) Describe what respite means to you?
- 2) How do you see respite playing a part in how you manage the care of your loved one?
- 3) Tell me about your experiences with respite care.
- 4) To your knowledge, what are the current respite services available to you in your community?
- 5) Do you access any of these services and tell me why you do or don't?

As I listened to the participants I was acutely aware of my own assumptions and biases regarding what respite is and why people may use or not use existing resources. Using a process of reflexive analysis, I kept an open mind and was very conscious of the necessity to refrain from asking questions that may be leading.

### *Analysis*

Data from the interviews were analyzed by extracting relevant information (observed and recorded), which was categorized, coded and critically analyzed in keeping with a qualitative approach (Streubert Speziale & Rinaldi Carpenter, 2003). Themes were then developed to define respite. Similarly concepts were identified that affected decisions to access respite services.

### *Study Limitations*

While this study adds valuable findings to the literature, it was not without limitations. Sample size was in keeping with a qualitative approach, however, it was heavily represented by those who had previously placed their loved ones in LTC. Caregiving does not end when this happens but the view point of respite may change somewhat. A recommendation for future study would be to increase sample size and interview those currently providing 24 hour care for their

loved one with ADRD. Another limitation identified was the sample represented only female caregivers from a small geographical area.

## Results

Regarding what respite is or how participants defined a break, two clear themes emerged from the data: surrendering and freedom. Knowledge was a third theme identified that contributed indirectly to the concept of respite or feeling relieved.

### *Surrendering*

Virtually all participants in this study spoke about coming to a place in time where they felt they had to give in. In the initial stages of caregiving, they felt able to manage it all whether as an individual or as a family and they did not feel they needed a break. However as the situation evolved into a longer experience, it was not uncommon to hear stories related to the deterioration of the care receiver, giving way to increased stress, and personal and family conflict for the participants. Participants then said it becomes apparent that you need a break and may need eventually to look externally for this. One participant who came from a strong family said,

*we actually have a couple of nieces that are nurses and a couple that are PCW's (Personal Care Workers), and there were four of us, so there was a lot of help available but what really surprised me more than anything was that we couldn't handle it ourselves ... it still baffles me that we had to give in.*

This family managed to get their break or respite from each other for several years before looking to external supports. That point may be different for each caregiver. Another participant said:

*everybody has to reach a point where they make the acceptance ... because even though you know what's going on, you don't accept it and until you do you can't look to others for*

*help because you think you can do it all yourself.*

Participants frequently spoke about their getting a break in terms of what would work for the care receiver before they would consider it for themselves. Surrendering to get a break often involved doing what the client wanted to prevent conflict, for example: “*buying maxi pads in bulk because she would be agitated if she didn’t have them, or letting them eat alone even though you want them to be with you*”. They would not surrender the care of their loved one to others unless it worked in the best interest of the care receiver. Surrendering care even if only for a few moments to accept help from others is paramount and logically participants reported looking to their family and friends initially before seeking outside help.

Surrendering care to get a break was seen as incremental. Many of the participants’ spoke of the necessity to seek help from outside resources as the loved ones illness became worse. This eventually led to the point of seeking placement, which is the ultimate surrender. Several participants alluded to the difficulty in letting go enough to let strangers into your home. However, placement was viewed as a given eventual surrender, but one that provided relief as reported by 10 of the 12 participants.

### *Freedom*

Freedom from the bulk of emotions that accompany the care giving experience was defined as getting a break, for example from anger, frustration, worry, guilt, fear, loss, loneliness, bitterness and exhaustion. Participants described getting a break consistently in terms of letting go completely emotionally and mentally even if only for a few moments. Although there was some mention of the need to have a physical break, the focus was strongly supportive of the need for mental freedom. Participants spoke of how structured and timed every moment of their lives

were and verbalized the need to have periods where time and structure were set aside. They spoke of this freedom from both short and long term perspectives.

*Short term freedom.* From a short term perspective taking a walk, having a bath, a coffee, watching TV, paying bills, going for appointments, supper when you wanted to have it and preparing what *you* wanted to have, an uninterrupted conversation with a friend and even doing housework without worry, were cited as offering periods of being free. One participant said she sometimes has a break even when her mom is with her. *“When she is having a good spell and is not being repetitive and always questioning I find this is a break, just to have the quiet. Sometimes we can even watch TV together.”* Working outside of the home was frequently defined as getting a break. One participant said *“I worked in peace, like I didn’t have to worry ... yeah I kind of just worked in peace.”* Another said this *“work was my salvation ... because you know we never went out anywhere, but when I went to work that was my out.”*

*Long term freedom.* Participants also spoke of having a break from a long term perspective. Longer breaks they spoke of involved, being alone in ones own home for a vacation, or going away for a vacation. These could involve weekend periods or longer periods of time. Making the final decision to place their loved one in a long term care institution was defined by 8 of the 12 participants as the hardest decision they have ever had to make in their lives, but all had come to terms with this. Long term freedom was never described by any of the caregivers as a necessary option in the earlier stages of the disease or caregiving experience. Rather it was an evolutionary process that resulted from deterioration of the loved one with ADRD and associated stress and decreased quality of life for the caregiver. By the time placement issues arose, the caregivers felt they were ready for the experience and they felt it would provide the best environment for their loved one as well. It is important to note the caregiving experience does not end with placement.

Participants with loved ones in these settings continued to visit daily and provide care for their loved one on a daily basis. Some comments made were:

*“Respite is a nursing home bed, we still go every day, but can come home worry free”*

*“Nursing home takes the worry out ... you can finally get a good nights sleep”*

All participants who had placed their loved one in a long term care setting however, expressed tremendous relief.

### *Knowledge*

Knowledge or lack of knowledge can indirectly affect ones break or relief. Knowledge is power and when empowered people may experience a sense of well being which can contribute to feeling emotionally free. Several participants said ‘*if only I had known sooner*’ relative to one of the following: knowledge of the disease process, knowledge that others share similar experiences, and knowledge of available services. One woman said

*I never even heard of Alzheimer’s disease and I didn’t know anything about it. I used to try to correct her all of the time and she would get so agitated, but I didn’t know then what was wrong and I kept on doing it. I would have done it differently if I knew.*

Knowledge can also be viewed from the perspective of care receivers. When they had moments of lucidity, contentedness and or happiness, this was seen as giving a break to caregivers. Another caregiver said “*their good day is your good day ... it gives you a break.*” Knowledge and confirmation of understanding from family, friends and health care providers contributed to feelings of peace and freeing the mind which also indirectly frees the spirit providing a break from the emotional baggage.

Eight of the caregivers have placed their loved ones in LTC settings and 2 more are currently considering this. In all 10 cases, it was the physician who suggested the time had come for

placement. Most expressed relief at having someone else suggest this, especially having the physician say it. Having the support of the physician likely removes some of the burden of decision from the caregiver. In the words of one caregiver who had suffered a small stroke herself just six months earlier

*I took her to the hospital one night because I just could not take it any more. I mean maybe if I had a sister or something to help me it would have been different. He [the doctor] said, 'I think it's time for a home,' and I looked at him, and I said, 'thank-you.' I wanted you to say that, but I didn't, but I did.. I had to go for counseling because I always swore to her I would never put her in a home. But I knew it was the best for her and for me.*

When LTC beds became available, some of the sentiments expressed by participants included,

*"Thank you God, because I knew it was time," or "that nursing home bed was a Godsend ... just a Godsend ..."* *"having her in a nursing home takes that worry away...like I can go to bed now at whatever time and have a good nights sleep and not worry about what she's doing. I know she is safe."*

Knowledge that the loved one was in a safe place and was getting good care contributed to relief for the participants. However, family members continued to provide support. Although, many needs of the care receiver are met in a nursing home setting, admitting them into this environment may help strengthen emotional and spiritual bonds with the caregiver as evidenced by the following comment:

*Even though she's in the nursing home and she's going to be well taken care of ... all of her physical needs are met ...but she needs one of us to be there. She needs the hug and she needs the kiss. and she needs the goodnight and she needs somebody to dress up*

*her bed every night. I'm there to do her nails or her pedicure, special stuff like that. So somebody has to be there at some point every day, one of the 3 of us .*

#### Decisions affecting access to respite services

Respite services currently available from the Nova Scotia Department of Health (NS-DOH) [Continuing Care Branch] are: community based respite offering a maximum of 40 hours per month which is not offered concurrently or overnight; facility based respite care wherein a bed in a long term care (LTC) facility can be accessed for up to 28 days per year at a reasonable cost; and adult day care programs. The province also has available 47 transitional beds provided in acute care centers' and managed by district health authorities. These beds are available to provide a bed for individuals who are unable to be discharged home and may need to stay until a LTC placement has been made.

While five of the participants reported using some government respite services, only 3 reported using community based respite to its full extent and none of the participants accessed the adult day care programs. Two reported all of the programs did not exist when they provided care, and one reported they were unaware of the services available. The remaining 4 participants were aware of the services available and were offered services but reported the existing programs did not meet their needs. All who were aware of the available respite services, reported the services as useful, however they freely discussed gaps that did not meet their needs. Existing support networks, financial means, caregiver continuity, flexibility, structure, and individuality were identified as having a role in whether respite services were accessed or not.

#### *Support networks*

Some of the participants had very strong support networks in the community and received their respite or breaks from family and friends thus had no need to access other services to fill

this need. Sometimes the break was defined simply as being taken for a drive or out to lunch together with the ill family member.

### *Financial means*

Two of the participants had the financial means (by family members all making financial contributions) to hire private assistance when the time came and felt this was a better option for their loved one than the government programs available. This allowed them the flexibility to choose one caregiver who they could call on when they were in need. This also provided continuity for the care receiver.

### *Caregiver continuity*

A lack of caregiver continuity was reported to be a deterrent to accessing respite service from the DOH program, although some say this has improved considerably. One participant said this “*it used to be you may have seven or eight different care providers in one week, at least now they only have two or three which is still hard but its an improvement.*” For clients with ADRD, familiarity is an important consideration; most participants said their loved ones did not like to be around strangers. However 1 participant did see value in having different homecare workers in any given week. She had this to say:

*Homecare has just changed their program and now we get the same person two times a week for our respite and another person two days a week and we used to have eight people, where there was a two day cycle and everyday it would be different and each person brought something different and some of them she likes and some of them she doesn't like, but that doesn't matter its because each person brings something different and each person reacts in a different way, and they all have their merits so having the same person three days in a row is not good for any of us.*

*Flexibility and structure*

Some caregivers verbalized that many aspects of their lives were scheduled and timed and when they needed a break, they needed this to be available when they needed it and not based on a predetermined schedule. Although they reported an understanding of why scheduling is necessary, the structure and largely inflexible scheduling of the government program, simply does not meet their needs. One caregiver said this

*The schedule drives me crazy, I have only two hours and I have to be back exactly on time. Do you know how hard that is? Everything is timed. If I meet someone I know when I am racing around paying bills or picking up groceries I can't say more than hello because I will get into trouble with the agency and I understand that but I hate it. I feel so guilty all of the time.*

Another caregiver had this to say:

*I was aware of homecare and the answer I got from them when I called was the respite from them, they were available to come in for eight hours a week. It could be a two hour time frame or it could be a four hour time frame but the total was eight hours a week. However I chose not to utilize them. Anyway, it had to be a planned thing and I wasn't really into planning, my life wasn't that structured and I didn't know when I would need them, therefore I decided not to access them.*

Participants were aware of adult day programs but none were able to access them due to long wait lists or inaccessibility for them. Some participants reported the hours of the daycare as not being useful for them, for example,

*They said they would come and pick her up but I would have to have a sitter here with her in the morning for an hour before they could get her. That would be the only way I could get to*

*work, so it was just no good for me.*

A few participants also expressed difficulty with tasks caregivers from the provincial program were not allowed to do, for example,

*They can't take them out even in the yard or to sit on the front steps because of insurance problems. They can't give a medication or even put a Band-Aid on, so you better make sure you do everything before you leave the house.*

Another complaint was if homecare workers were in to do another task such as bathing the client for an hour, the informal caregiver is not allowed to leave the home as this is not assigned respite care. The structure of the homecare program simply does not allow for individual differences among caregivers. In fact it may add barriers.

### *Individuality*

Although many similarities exist between caregivers of ADRD clients, each person and each situation is unique and thus individuality becomes critical when planning programs of care.

There is no one size fits all approach. One approach simply does not fit every situation and when respite is viewed as an outcome rather than as a service, only then will consideration be given to individual clients' based on what will work for them. This small study clearly shows that current respite programs are not being used to their full potential because respite continues to be viewed as a service.

### Discussion

The findings in this study concur with other similar research study findings. Respite should be viewed as an outcome rather than as a service. The stories shared and lessons learned from the participants in this study have helped redefine respite as this: 'respite is a phenomenon arising out of the loving bonds of the caregiving experience necessitating individualized self defined

periods of time wherein one is afforded relief emotionally, physically and spiritually.” Often in the earlier stages of the caregiving experience or for those with strong family supports, the ‘break’ is self managed; sometimes by just having a moment of quiet reflection. Although there remains a need for respite services, those in existence should be tailored to meet the needs of caregivers, particularly those providing care to loved ones with ADRD.

The participants in this study generally agreed that as the functional and mental capacity of the care receiver decreased, their need as a caregiver to ‘let go’ becomes more critical. The need to surrender and have moments of freedom in the form of a break does not always equate to the need for external ‘respite services.’ However, when it does, existing services are often perceived as not meeting defined needs. This is a critical consideration when examining why those who need these supports most, do not access them in a way that would be expected. As a follow-up, it is recommended that a full scale mixed method evaluation of existing provincial respite services be undertaken initially in Nova Scotia involving this representative group, specifically for those currently providing care.

Respite as a service is often viewed as a way of delaying LTC placement (Feinberg & Kelly, 1995). There is no connection made in the literature between respite and LTC placement; permanent nursing home placement is not viewed as a ‘break.’ Yet the participants in this study clearly defined it as the final surrender and freedom, particularly emotional freedom. This ironically may ultimately contribute to strengthening emotional and spiritual bonds between the caregiver and care receiver which become fragile over time. While initially described as one of the hardest decisions ever made, participants allude to eventually finding an inner peace or freedom from the day to day emotions connected with providing 24 hour care per day care. Though they continue to provide some care for their loved in the LTC setting, they are provided

with a great deal of relief. This is an area in need of more study as one weighs the costs of delaying nursing home placement against keeping loved ones in the community with current support systems.

Many of the ways in which participants defined respite would not be found available from existing respite programs which could be streamlined and individualized to meet differing needs. Although many similarities exist among participants, there is no doubt every situation is very much individualized. Innumerable variables are at play. Flexible programming is a consideration for all respite programs. Needs should be assessed on an individual basis and care givers then assisted in appropriate ways to meet their needs. It is also important for respite services to consider ways in which caregivers can be empowered. Providing them with the tools they need in the form of knowledge is an important consideration for contributing to their relief.

Many participants in this study made reference to waiting to hear the physician tell them it was time to place their loved one in a long term care setting. This suggestion from a health care personnel validated for them what they already knew but were afraid to come to terms with. A consideration for practice may be to suggest more frequent and all encompassing assessments for those providing care for their loved ones with ADRD. Opportunities for earlier intervention in addressing these needs may yield better outcomes. The outcomes may be earlier placement or other interventions that would help caregivers cope better and delay placement. Future studies would be warranted in this area.

This study while representing caregivers of loved ones with ADRD, was largely composed of participants who were now removed from the care giving experience. A larger scale study of this representative group, specifically for those currently providing care would add validity to the growing body of knowledge in this area.

### Conclusion

This study provides a snapshot of a small group of caregivers providing informal care to their loved ones with ADRD. Findings validate previous research that views respite as an outcome (Anderson & Parent, 2006; Chappell, 2001; Meredith & Meridith, 2003) rather than as a service which has implications for practice. Respite was categorized into two main themes: surrendering and freedom with knowledge found to contribute indirectly to the concept of respite or feeling relieved. Several factors were identified as having an impact on the decision regarding whether or not to access existing respite services. This study adds to the growing body of knowledge that respite should be viewed as an outcome rather than as a service, particularly for caregivers managing loved ones with ADRD. Respite services are still very much warranted but should be re-evaluated based on client needs.

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