

Evaluation of a Weekend Respite Program for Persons with Alzheimer Disease

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Dans un contexte où les besoins des prestataires de soins familiaux demeurent insatisfaits, la sous-utilisation documentée des programmes de soutien moral génère des interrogations. Cette étude avait pour objectif l'exploration du vécu des prestataires de soins familiaux en rapport à un programme pilote de soutien moral qui offre des soins pendant les week-ends aux personnes atteintes de la maladie d'Alzheimer ou de la démence qui s'y rattache. L'approche d'évaluation sans objectif a permis de recueillir les réactions de 18 prestataires de soins familiaux face à un programme pilote qui a été mis sur pied par un organisme communautaire œuvrant en soins infirmiers. Une analyse de contenu des entrevues menées auprès des prestataires a permis d'identifier trois catégories : la capacité que possède une prestataire à prendre soin d'elle-même, la sécurité du membre de la famille ainsi que son bien-être. Les résultats obtenus suggèrent l'existence d'un lien entre le soutien dont bénéficie la prestataire de soins familiaux et la sécurité et le bien-être dont jouit le membre de la famille. La perception des prestataires concernant les coûts et les bénéfices générés par le soutien influence la fréquence à laquelle elles ont recours aux services dispensés dans le cadre du programme. Les conséquences en matière de recherche font l'objet d'une discussion.

The documented under-use of respite programs in the face of unmet family caregiver needs is puzzling. The purpose of this study was to explore family caregivers' experience with a pilot respite program of weekend care for persons with Alzheimer disease (AD) or a related dementia. The goal-free evaluation approach captured the responses of 18 family caregivers to a pilot program developed by a community nursing organization. A content analysis of the caregiver interviews identified 3 categories: caregiver self-care, relief for the caregiver, and safety and comfort of the family member. The results suggest a link between the family caregiver achieving respite and the safety and comfort of the family member. The caregivers' perspective regarding the costs and benefits of respite influences the frequency with which they use the program. Research implications are discussed.

The Canadian Study of Health and Aging (Canadian Study of Health and Aging Working Group [Canadian Study], 1994) reports that 8% of the population aged 65 and over and 34.5% of the population aged 85 and over are diagnosed with dementia. Alzheimer disease (AD) is the most frequently diagnosed type of dementia included in these figures.

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As the number of people with dementia increases so too does the work of the family, since family members often provide care to persons with dementia at some point during the course of the disease (Baumgarten, Battista, & Infante-Rivard, 1992; Keady, 1996; Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). The median length of time spent caring for people with AD is 6.5 years (Haley, 1997). Of all family caregivers, women are the largest group, while spouses are the first in the family to take on the caregiver role (Abel, 1990; Coward, Horne, & Dwyer, 1992; Haley, Pruchno, & Resch, 1989; Stone, Cafferata, & Sangl, 1987). This paper reports on an evaluation of a respite program for families seeking relief from caregiving duties.

Currently there is no reason to suggest that dementia will recede as a major concern until researchers identify some causal variable that is amenable to intervention (Canadian Study, 1994). Thus, persons with dementia and their family caregivers pose a considerable challenge for Canadian nurses who encounter both in numerous settings.

As research has established, stress and burden are among the more frequently identified consequences of caregiving, especially if the care recipient has dementia (Miller & McFall, 1992; Robinson, 1990; Zarit, Todd, & Zarit, 1986). Other consequences are depression (Baumgarten et al., 1992; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Parmelee, 1992), insomnia, and anxiety (Baumgarten et al.; Pushkar Gold et al., 1995; Robinson & Steele, 1995).

In contrast to the negative aspects of caregiving, a small but significant body of research has identified rewards and points of satisfaction. Caring for a loved one may become an integral part of one's identity and provide opportunities for one to demonstrate commitment and reciprocity (Cartwright, Archbold, Stewart, & Limandri, 1994; Guberman, 1999; Morgan & Laing, 1991). Currently there is no model or theory for evaluating the relationship between positive and negative consequences of caregiving. In both practice and research, caregiving is recognized as a mixture of positive and negative outcomes because it is a complex process involving long family histories.

The family caregiver's need for assistance and support in the form of respite is recognized in the literature, but respite has had mixed results in terms of demonstrating effective outcomes (Guberman, 1999; Homer & Gilleard, 1994; Knight, Lutzky, & Macofsky-Urban, 1993; Shantz, 1995). As an intervention, respite is compelling to practitioners and researchers because of caregiver interest and demand, and is con-

fusing because even when made readily accessible it remains under-used. In this paper, we present findings from a pilot respite program and describe the family caregivers' overall experiences with it. We discuss the identified caregiver categories in an effort to enrich our understanding of the respite experience.

Literature Review

Inconsistencies in definitions and conceptualizations plague the respite literature (Strang & Haughey, 1998). Respite programs differ in structure and function and in terms of desired and expected outcomes (Smyer, 1999). Most research studies and literature reviews provide operational definitions that include caregivers leaving their kin with an informal (volunteer) or formal (paid) care provider (Rudin, 1994; Smyer; Theis, Moss, & Pearson, 1994; Worcester & Hedrick, 1997). These definitions also include the location (in-home or institutional) of the respite as well as the length of the stay (Rudin).

Some authors claim that respite is a unique intervention from which both the caregiver and the client derive benefits (Rosenheimer & Francis, 1992; Strang & Haughey, 1998; Theis et al., 1994). Other studies describe respite as prolonging a care recipient's ability to remain in his or her own home and thus delaying long-term placement (Kosloski & Montgomery, 1995; Lawton, Brody, & Saperstein, 1989; Rosenheimer & Francis; Shantz, 1995), although this finding has been questioned.

Strang and Haughey (1998) place respite in the mind frame of the caregiver, prohibiting a program from claiming respite as a positive outcome unless it has been a positive experience for the caregiver. They conceptualize the caregiver's experience of respite as "a cognitive process of getting out of the world of caregiving and into their own world. In this world, they feel free from the responsibilities and worries of caregiving" (p. 231). It has been proposed that a caregiver's positive perception of respite is linked to the assurance that the client will benefit from the experience (Rosenheimer & Francis, 1992; Strang & Haughey; Theis et al., 1994).

As the literature indicates, the lack of a standard definition is problematic, pointing to deeper issues regarding the nature and purpose of respite programs. Issues such as *where* respite occurs pale in comparison to the discrepancies in *how* it occurs and whether it is defined by the program or by the experience of the family caregiver. Until these issues are addressed, an acceptable standard definition will not be possible.

Respite: Outcomes and Utilization

Respite outcomes. The respite literature falls into two distinct categories: studies that measure and describe outcomes and studies that evaluate utilization. The outcome literature suggests that positive outcomes for the caregiver are minimal at best. Some studies have found that while family caregivers described their reaction to respite in somewhat positive terms, their scores did not change significantly on measures of well-being (Lawton et al., 1989) or general health (Homer & Gilleard, 1994). Many of the eligible families did not use the services described in the study, resulting in the elimination of a large number of potential participants from the sample. Interestingly, Homer and Gilleard found that family members often visited the care recipient while he or she was in respite care. Reasons for visiting included missing the care recipient, feeling guilty, and wishing to ensure quality of care. In this group not all the care recipients had a diagnosis of dementia.

In a study by Larkin and Hopcroft (1993), caregivers reported a significant reduction in their psychological distress as measured using the Global Severity Index (GSI) while their kin was in a respite program, but this reduction was not sustained. Richey and Hodges (1992), in a case analysis of a woman caring for her elderly mother with dementia, also identified positive outcomes of respite. The daughter increased her time away from home, enjoyed the respite, and had a significant score change on the Child's Attitude Toward Mother scale when respite care was in place.

A grounded theory study by Worcester and Hedrick (1997) described the dilemmas of respite care and found that family caregivers characterized their relationship with formal care providers as "imposing." "Imposing" situations were those in which the family caregiver asked the formal care provider for special consideration, as well as when the formal care provider was demanding, made unwanted suggestions, or interfered with the caregiver's routines and approaches. The theory described the conservation of energy and resources as the central concern of the caregivers, and found that respite depleted rather than conserved energy and resources. In contrast, the evaluation of a descriptive program found that caregivers took the time to rest, socialize, or tend to their own health needs, while the clients benefited from the socialization with other people, the new surroundings, and the stimulation that family caregivers were not always able to provide (Rosenheimer & Francis, 1992). These studies also demonstrate the lack

of an acceptable standard conceptualization of respite to guide program development and evaluation — it is not clear that the respite programs actually failed, but it is clear that there is no well-supported way of evaluating them.

Resource utilization. Some of the resource utilization literature addresses the question of why family caregivers do or do not use formal supports such as respite. It also explores the under-utilization phenomenon more generally. King, Collins, and Liken (1995) found that families “owned” their difficulties, protected vulnerable members, and were self-reliant units, and that family boundaries governed help-seeking. A different perspective is reported by Adler, Kuskowski, and Mortimer (1995), who found that caregiver attitudes did not predict respite use. Strang and Haughey (1998) identify the factors influencing the caregiver’s experience of respite as: the nature of the relationship prior to the onset of illness, the caregiver’s role expectations, the type and quality of the respite service, and length of time in the caregiving role. Strang and Haughey’s findings support Rudin’s (1994) finding that the caregiver’s view of the program and its effect on the kin influences attitudes towards respite care and the use of respite services. O’Connor (1999) also identifies role expectations as a factor influencing under-utilization of services. She suggests that giving up the caregiving role and accepting assistance could jeopardize the caregiver’s sense of identity, even when the assistance is needed. Both O’Connor and Smyer (1999) call for research that addresses the meaning of service utilization to the caregiver.

Kosloski and Montgomery (1995) bring together the topics of outcomes and utilization. They point out that not knowing why family caregivers avoid or refuse respite precludes full program implementation, and that this circumstance has a built-in bias against results that demonstrate positive outcomes. They also note that, “perhaps most importantly, researchers and policy makers have yet to identify exactly what outcomes are appropriate for respite evaluations” (p. 73).

Thus the difficulties identified in the literature include inconsistencies not only in definitions but in the very conceptualization of what respite is and for whom it is intended. The fact that there are very different approaches to respite evaluation is therefore not surprising. The magnitude of these differences in definition, intention, and evaluation suggests that it is time to revisit respite, and to pursue in-depth explorations of the experience.

Design and Method

One western Canadian agency responded to the need for respite services by extending its Adult Day Program (ADP) to include weekend care as a pilot project. The expanded operation served to increase the options for family caregivers. While people with AD or related dementia participated in a therapeutic program, family caregivers had ready access to weekend relief.

The ADP operates as an eight-bed overnight respite service from Friday afternoon to Monday morning. The physical environment is fashioned to mirror the client's home. The bedrooms are large single rooms with matching comforters, drapery, and borders and a private bathroom. Family caregivers completed a care booklet containing information on the habits and preferences of the person with dementia. The program is designed to give clients the freedom to maintain personal schedules and routines; for example, one woman "slept in" on the weekend. The daily plan is relaxed and staff members encourage activity according to client preference; for example, many program participants enjoy walking, and that is always arranged when weather permits.

A qualitative evaluation was undertaken to explore the family caregivers' experience with respite. While the total evaluation included input from staff (focus group) and clients (interview and participant observation), only the family caregivers' evaluation is presented here. The agency initiated and was responsible for ethical review. Caregivers were informed that they were free to refrain from talking with the researchers and that failure to participate would not jeopardize the care of their family member. An advisory board composed of three current users of the program helped focus and guide the development of the evaluation. The advisory board stressed the need for a personalized approach and spoke strongly against the use of instruments because of the general fatigue associated with filling out forms and, more importantly, because they did not think questionnaires could capture their unique experiences.

The most suitable approach to the family caregiver data was goal-free evaluation. Patton (1990) supports this technique because it "opens up the option of gathering data directly on program effects and effectiveness without being constrained by a narrow focus on stated goals" (p. 117). He further explains that "goal free evaluation, in its search for *actual* effects, is an inductive and holistic strategy aimed at countering the logical deductive limitations inherent in the usual quantitative goal

based approach to evaluation" (p. 116). Patton's approach was particularly important for this project because, as discussed above, respite evaluations were not demonstrating significant effects using the traditional measures of stress, burden, well-being, and general health. In addition, as we have seen, appropriate outcome measures have not been established.

The data reported here were collected through telephone interviews that were tape-recorded and transcribed verbatim. The researchers asked specific demographic questions and obtained general information such as frequency of use. However, most questions were open-ended ones inviting the caregivers to talk about their experiences. They included: "How did you spend the time while _____ was attending the program?" and "How do you think _____ experienced the program?" Since the literature indicates that the caregiver's view is part of the respite experience, we considered it important to ask the latter question. However, the caregiver's response was not used in determining the actual experience of his or her family member.

Sample

A total of 25 family caregivers used the service over a 6-month period, and efforts were made to include the entire cohort of program users. The data reported are from 19 caregivers. Six caregivers were not included in the evaluation: five did not respond to repeated phone calls and one was not contacted because of the recent death of the family member with AD. The caregiver sample represents the major family roles of husband, wife, daughter, and son, as well as one sibling and one granddaughter (see Table 1). Of the 19 family caregivers, eight used the program between three and 12 times (see Table 2).

Analysis of Qualitative Data

The authors reviewed the data to identify themes and ideas. The latent form of content analysis directed the researchers to explore the meaning of the text through the words of the participants, rather than by setting and naming the categories before carrying out the analysis. The process resembles constant comparative analysis in that the researchers constantly move back and forth between the text and the emerging codes (Catanzaro, 1988). The units coded included words, phrases, or whole sentences that captured or reflected a single idea. The codes were brought together when they formed identifiable themes (Miles & Huberman, 1994). The transcripts were coded separately and then dis-

Table 1 *Relationship of Caregiver to Person with AD and Caregiver Age*

Relationship	Number	Age (years)
Husband	2	73, 80
Wife	8	71, 71, 63*
Daughter	3	49**
Son	3	33, 52***
Granddaughter	1	28
Sister	2	71, 65
n=19 * missing 5 ** missing 2 *** missing 1		

Table 2 *Frequency of Program Use*

Caregivers	Number of Times Program Used
11	1
2	3
1	4
3	5
1	7
1	12
Note: Program used a total of 65 times	

cussed until consensus was reached on the categories and themes. The manager and the director of the program reviewed the codes and themes before the final consolidation of the findings but suggested no changes.

Results

Based on the potential of eight beds per weekend for 24 weeks, 34% of the weekend respite beds were used (65 beds out of a potential 192) over the 6-month period. From the data obtained concerning utilization during this time, the researchers identified that the program enabled the family caregivers to achieve respite and derive satisfaction from it. Three categories were identified from the data analysis, two of which contained subcategories or themes that enriched our understanding of the caregivers' view and experience of respite. The three categories were: caregiver self-care, relief for the caregiver, and safety and comfort of the family member.

Caregiver Self-Care

The category of caregiver self-care identified the strategies used by the caregiver to promote his or her physical, social, and emotional well-being. Three themes appeared frequently: maintaining family and social relationships, maintaining own health, and catching up on sleep and rest. In essence, these themes demonstrated the caregiver's proactive use of the time gained by participating in the program.

It is clear from the interviews that caregivers used the respite service as a means of fulfilling their own needs. Yet the caregivers also expressed concern about the well-being of their family member with dementia. Many commented on positive aspects of the program such as the social and physical stimulation of their family member.

Maintaining family and social relationships. Caregivers used the respite program to pursue pleasurable activities, to visit relatives who did not live nearby, and to see friends and make new friends. They found opportunities to seek out and engage meaningfully with family and friends. For one caregiving wife, travelling to be with family was clearly important:

I have a son that lives in [a nearby island] and I went to visit him and I am going to do it again when my granddaughter graduates. I want to go to her graduation, you know, he [husband with AD] won't enjoy it.

The comments of another wife highlighted the importance of engaging in activities and building friendships outside the caregiving experience:

Well, the thing is that I belong to the bluegrass society and folk song society . . . at the end of June they have three days of music at camp . . . a friend of mine — she's 76 — and I go . . . At the end of September there's a bluegrass festival. I'm going in a tent and the whole works . . . That's the thing that I do. I love music. That's how I make my friends.

An interview with a caregiving granddaughter illustrated the impact of caregiving on all members of the family and the need for weekend respite:

I spend more time with the kids . . . You see, we all basically live our lives around her schedule . . . [During the week] between the three [kids] and Grandma it is who can yell the loudest to get the attention — so [the respite program is] a big help.

Maintaining own health. Some caregivers needed time to deal with their own health issues. A caregiving spouse described the service as a "godsend" because she was able to admit her husband for weekend

care when she was ill. Others also described weekend care as an "emergency" service — during flu season, for example.

Several caregivers used the time to deal with their own psychosocial health needs, by relaxing, spending time outdoors, or being by themselves or with their partner.

One woman said, "I didn't go away, and I found that it was more beneficial just having the weekend, rather than going away and it being hectic and then coming home and being tired." Another woman indicated that respite gave her time to be alone with her spouse: "We get to go out for meals and do some other activities and things."

Catching up on sleep and rest. There was an overlap between maintaining health and getting sleep and rest. However, the caregivers focused particular attention on the area of sleep and rest, as captured in the following statements: "We have a monitor at night. We're often up two or three times a night, so putting her in respite allowed us to have a good night's sleep." "I slept . . . I was exhausted."

Relief for the Caregiver

Relief for the caregiver was very much the core of the respite experience but was difficult to capture. For example, participants did not clearly distinguish between stress and worry but were certain of which term they wanted to use. Here, relief is defined as the temporary alleviation of distress (stress and worry) or the responsibility of caregiving. The caregivers spoke of having a period of time when they could be free from stress and worry. One caregiver said, "This way actually it helps us a bit with the stress . . . you feel you can let go for a little bit and somebody else has the responsibility." Another reported:

I think it's a wonderful service. It gives me a break, because I worry about him all the time. It gives me a chance to get out with friends and know that he's properly taken care of. I know that they are very good to him there. . . he feels more at home there.

Another caregiver said, "It's some place where I can leave her and not have to worry, and that's a big thing." The caregivers' ability to actually feel relief appeared to be tied to the knowledge that their kin was safe and well. The following section describes this relationship.

Safety and Comfort of the Family Member

The category of safety and comfort is defined as the caregiver's evaluation of the program in both process and outcome. The process criteria

that caregivers identified were opportunities for socialization, meaningful interaction, and sensory stimulation. One caregiver described the opportunities for socializing as: "She also gets to meet . . . and talk with different people; she's pretty well stuck in the house here." Caregivers identified the need for the person with AD to have the "right amount" of stimulation: "He needed the stimulation, which I couldn't provide for him, of other people and programs, and this [the respite program] was very good." Some caregivers identified specific activities that were important to their family member, such as field trips to local gardens and going for walks near the centre.

On the other hand, one family caregiver voiced a concern that socialization within the program might be less than optimal:

. . . the first time he came to [the respite program] I think he felt that there weren't as many people around as he wishes to have, not that he has them at home but he goes to [a different centre], you see, and he's been to those other places and there's always lots of people around.

The family caregivers used the criteria of emotional state and physical appearance to evaluate the client's safety and comfort levels. They apparently assessed their kin both when they left for the centre and when they returned home. Some commented on the emotional state of the client: "He always comes away quite happy and looks like he had a really good time." "He seems quite tickled there, and it gives him a break away from home, because he gets kind of bored being always at home, and getting a break away actually does him good, because he's happy to get back home."

Family members also reported on the client's view of the experience: "My wife has remarked several times since then how good it was . . . how much she enjoyed it." "My wife frequently recalls people by name, people who were so nice to her, and how good they were. She raves about [the respite program]." "He thought [the staff] were great. He thought the food was good too." This data supports the idea of a relationship between the caregiver's ability to experience relief and the caregiver's perception that his or her relative is comfortable and safe.

Caregivers differed in their perceptions of the cost benefit ratio of respite care. All agreed on the difficulty of getting the client packed up, transported, and settled at the facility, with the client sometimes feeling angry or crying. However, some caregivers, particularly the multiple-program users, perceived the benefit to themselves and the physical and emotional benefit to their family member with AD as warranting all the trouble.

Discussion

The difficulties that arise in trying to capture the feelings and meaning of relief associated with respite are complex. This may account for the lack of positive outcomes identified in much of the respite research. We believe that some of the traditional quantitative approaches to respite, which are intended to decrease stress and burden, may be inappropriate. Our findings suggest that caregivers cannot feel and experience respite until they are assured of their kin's safety: there is a link between the caregiver's ability to experience respite and the assurance that the client will also benefit from it. These findings support those of Strang and Haughey (1998), in whose study caregivers described the attributes of respite that facilitate the experience of relief. Likewise, Rudin (1994) and Theis et al. (1994) found that caregivers judge the usefulness of a program on the benefits that both they and their kin derive from it.

Clearly, the need to attend to their own basic human needs was important to the caregivers in this and other studies. Larkin and Hopcroft (1993), in investigating caregiver stress before, during, and following respite, found that caregivers described improvements in sleep functioning and health, both of which they considered major benefits. Equally clear is the need to maintain family and social ties and avoid the social isolation described in the literature (Guberman, 1999). The flexibility of the weekend respite program optimized the caregivers' ability to participate in social and family activities. While these informal networks are the most effective means of achieving affective support (Bergman-Evans, 1994; Cohen, Teresi, & Blum, 1994; Theis et al., 1994), accessing them is difficult when respite care is limited (Richey & Hodges, 1992).

Our findings also support those of researchers who identify the temporary relief that accompanies respite. The caregivers interviewed for the present study described the lowering of stress as a short-term effect of respite. Although the relief was temporary, some of the family caregivers elected to use the program repeatedly. Other researchers echo the finding that the effects of respite are temporary (Adler et al., 1995; Larkin & Hopcroft, 1993).

Though this study contributes to our understanding of the respite experience for caregivers of kin with dementia, it is not without limitations. Most obvious is the fact that the findings are not generalizable. We do not have data from people who were fully aware of the new program but decided not to use it, or from people who were drawing

on other respite options in the community. Though family members were told that no identifying information would be shared with the program staff, participants may have been reluctant to share all of their thoughts and feelings.

In summary, it seems clear that the more traditional approaches to respite care could be replaced by models such as that of Strang and Haughey (1998), in which the experience of the caregiver is the focus. One could also argue for a more family-centred model that encourages researchers to explore the caregiver's description of what happens to their kin, thereby accounting for both members of the caregiver-care recipient dyad. An approach that reflects the findings regarding the caregivers' need for security and quality of care for their family member could help maintain family identity and reduce the feeling of abandoning or "handing over" a loved one. We see this as the next item on the agenda for respite research in Canada.

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