
The Respite Experience: Family Caregivers and Dementia Patients

Caring for a family member with dementia can be stressful. Respite services are seen as a key formal supportive intervention mitigating these negative consequences of family caregiving. This paper presents a descriptive model of caregivers' respite experiences within the context of caring for persons with dementia.

by Vicki Strang, RN, PhD

It is well recognized that family caregiving, particularly with dementia patients, can result in such negative consequences as deterioration of physical health, social isolation, severe time restrictions and negative emotional reactions.^{1,2} Caregivers have repeatedly indicated respite as one of their most pressing needs,³ and have been offered services called respite care. Respite commonly is defined as an interval of rest or relief, and as temporary relief. We have assumed that caregivers who use respite services experience an interval of rest and temporary relief. Many caregivers, however, are reluctant to use available respite services,^{4,5} such as day and night sitter services, adult day programs or temporary stays in institutions. We have had difficulty explaining this discrepancy. This difficulty might be related to the fact that we have not adequately explored what respite means to caregivers. The purpose of this paper, therefore, is

to present a descriptive model of caregivers' respite experiences within the context of caring for people with dementia, and to highlight the related critical practice implications.

The Study

The research work described in this paper was conducted within a qualitative interpretative framework. Guba, Lincoln⁶ and Schwandt⁷ indicate that, within the interpretivism orientation, knowledge is generated from a subjective and dynamic uncovering of individual meanings and the human experience. The aim of this type of enquiry is to understand, rather than explain, the actions of individuals and the meaning they attribute to those actions. The generation of new understandings are based on the empathic understanding, by the researcher, of how individuals make sense of their world. Therefore, the caregivers and the researcher together focused on how caregiving was being experi-

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enced, how respite was perceived within that experience, and what allowed the caregivers to consider respite for themselves.

Data were collected through in-depth open interviews of between 60 and 90 minutes each. All the interviews were transcribed verbatim. The transcriptions were checked for accuracy and edited for identifying information. As well, detailed notes about the home environment and family situation at the time of each interview were kept. The research interviews were guided by the following questions:

- What is the caregiver experience of respite?
- How do they define respite?
- What does it mean to them?
- When do they experience respite?
- How important is it to them?
- After having a respite experience, how does it feel to resume caregiving responsibilities?

The number of participants was determined as the data categories emerged from the interviews, became saturated, and the conceptual and theoretical linkages became evident. In this series of studies, 31 family caregivers (25 women and six men) were interviewed individually. Fifteen of the 31 caregivers were interviewed twice, with a two-month lapse between interviews. These second interviews served as validation, and determined consistency in the interpretation of the caregivers' narratives. There were 22 spouses, eight adult children and one niece in the study. Their ages ranged between 45 and 85 (mean 76) years. Their education ranged from incomplete secondary schooling to post-secondary and advanced university achievement. By self-

admission, the study caregivers' experiences included dementia related either to Alzheimer's disease or vascular insufficiency.

The Descriptive Model of Caregiver Respite

Each component of the model, as shown in Figure 1, will be described in the following section. Two aspects of the model already have been published,^{8,9} while a third component is in review. Integrating all the components into one model is the unique contribution of this paper to our understanding of the family caregiver respite experience.

The study caregivers, in the descriptions of their respite experiences, created an image of two spheres of existence. One large and dominating sphere was the caregiving world, while a much small-

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er, but very special, sphere was that part of their lives where they experienced respite and where they were not caregivers. Getting to this special personal space was a cognitive process of "getting out" of the caregiver world, and was not necessarily linked to using respite services. For the caregivers, the quintessential meaning of respite was to be in this special personal cognitive space where they felt "free" to be themselves, to pursue their own interests and activities, to stop worrying about their dependent loved one, and to not be the caregiver. For a short interval of time, they could shed the responsi-

bilities of caring for their dependent family member and focus on themselves in their activities. This opportunity to get out of the caregiver world and into "their own world" was identified as a strong coping strategy for the caregivers.

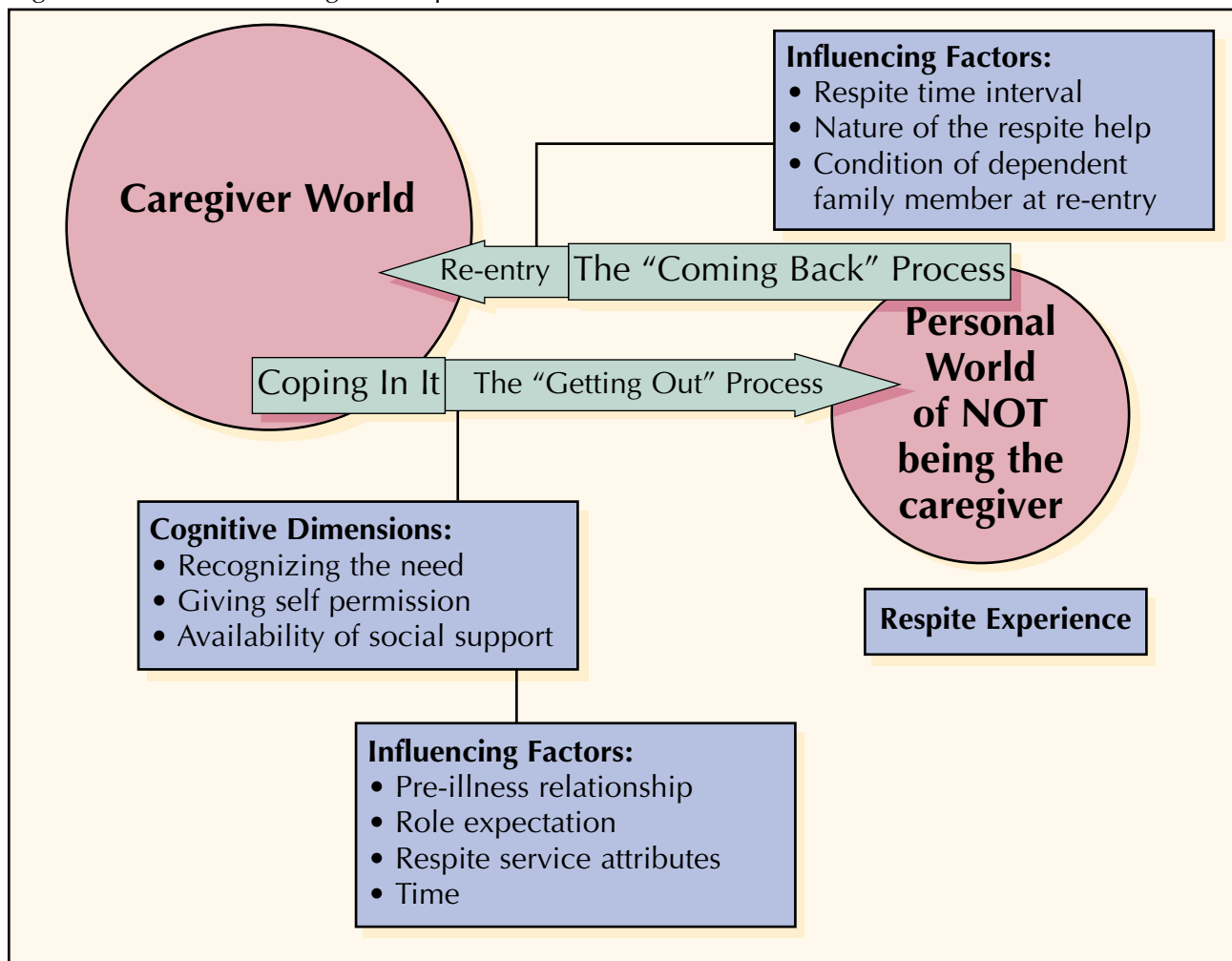
The "Getting Out" Process: Cognitive Dimensions

A number of cognitive elements, and the notion of movement toward a mental place where they would consider themselves out of the caregiver world, emerged from the caregivers' interviews. There were at least three cognitive phases evident in their descriptions.⁹

The first phase was the recognition by the caregivers of their need to get out of the caregiver world. The second phase seemed more complex and difficult for some caregivers, because the recogniz-

ing behavior did not necessarily translate into actively getting out of the caregiver world. In this step, the caregivers had to admit to themselves that it was okay for themselves to get away from the responsibilities of caregiving for a while. Additionally, they had to come to an emotional resolution that this type of self-serving behavior was appropriate. The third phase was caregiver recognition of the availability and adequacy of social support resources. For example, one caregiver said she recognized the need for respite and cancelled the service because of guilt. It was only with consider-

Figure 1. A Model of Caregiver Respite



able encouragement from both her formal and informal support systems that she finally recognized and accepted that the respite service was available for her to use. If this caregiver had been left to her own devices, she might not have overcome her ambivalent feelings about using a respite service.

The "Getting Out" Process: Influencing Factors

Factors influencing these cognitive dimensions included the nature of the pre-illness relationship between the caregiver and the dependent family member, the caregiver role expectation, the attributes of the

available respite services, and time.⁸ The pre-illness relationship's influence on the caregiver's ability to get out of the caregiver world was exemplified by one caregiver who talked about how it had always been her style to give in when she and her husband were having an argument. Rather than argue with her husband about going to a day program or using an institutional respite placement, which he did not want to do, this caregiver said she would defer to his wishes and keep him at home. This made her resentful of his inflexibility and her own inability to get the respite she so desperately needed.

Caregiver role expectation was another factor influencing the ability of the caregivers to get out of their caregiving world. For example, one caregiver talked fondly of the good life she and her husband had together and said that, even though her present circumstances were difficult, she felt content. She could not conceive of doing anything but taking care of her husband.

Another influencing factor was the respite services attributes. Caregivers identified numerous respite program conditions which influenced their ability to get temporarily away from their caregiving. These conditions, as interpreted by

the caregivers, and which were not the same for every person, included the acceptability of the respite service to the dementia patient, the willingness of the patient to use the respite help, the respectful attitude of the personnel in delivering the service to the patient, the service's beneficial features for the patient, and the legitimization of the respite help by someone in authority.

A final factor influencing the caregiver's ability to move out of the caregiving world was the length of time they had been in that role. It took three years for one caregiver to realize she needed to get away from the caregiving for short periods of time so she could continue in it.

The "Coming back" Process

Inherent in the experience of respite is the resumption of the caregiving role. Having experienced the freedom of respite, the caregivers always had to come back to their world of responsibility and caregiving.¹⁰ The anticipated outcome of the respite experience was emotional and physical refreshment and renewal. This certainly was evident in some of the caregivers.

The "Coming Back" Process: Influencing Factors

How caregivers experienced re-entry into the caregiver world depended on certain factors, including the duration and quality of the respite interval, the nature and quality of the respite help that was used for the dependent family member, and the condition of this family member when the caregiver resumed his/her caregiving role.

The duration and quality of the caregiver's respite interval influ-

enced their re-entry in a number of different ways. Shorter intervals of free time, such as those provided by adult day programs, matched the ebb and flow of the caregivers' daily lives and was used to run errands and/or do chores. It also was used by some to engage briefly in personally satisfying activities.

When the time was used to do errand-type activities, it did not seem to be associated with respite. For example, in the research interviews, caregivers rarely considered adult day programs as respite, even though they might be using such a

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program. It was only with prompting about their use of the adult day program that caregivers discussed it in relation to their respite experience. They saw these short-interval programs as ways of providing some time (and in many cases, not enough time) to do the chores they were unable to do in the presence of their dependent family member.

When short-interval time was used for planned, personally satisfying activities, it allowed only enough time to do the essential components of that activity. There wasn't enough time to experience the activity fully, and the brevity of the time interval interfered with the caregiver's full enjoyment of the activity.

Because these activities were so closely tied to the contextual patterns of their daily lives, the caregivers did not seem to have diffi-

culty returning to their caregiving responsibilities. Re-entry was routine, low-key and emotionally uneventful. Despite the hassle of managing these rushed activities, short respite intervals still could be associated with feelings of refreshment and renewed energy.

On the other hand, longer intervals of respite, such as those afforded by institutional respite services, seemed to provide more of the personal freedom time that study caregivers associated specifically with respite. The re-entry from this type of respite experience was varied and more emotionally

charged. The caregivers who had used this longer interval of respite talked of being glad to see their relatives again, of feeling good about being home and of conversing with their family member about their different experiences while they were apart. The caregivers talked of feeling emotionally better about their caregiving, of having more energy to do their daily activities, of being more accepting of their circumstances, of not getting angry as quickly and of being more tolerant and patient with their loved one. This re-entry usually was associated with positive emotions. Longer respite time seemed to provide caregivers with the renewed energy and revitalization they require to carry on with their caregiving responsibilities. Additionally, it seemed that both short and long intervals of respite improved

the relationships between caregivers and their dependent family members.

The quality of the respite time, rather than its duration, was another factor that influenced caregiver re-entry. Caregivers talked of it as a rare “peak” experience which was highly valued by those who experienced it. This type of respite interval was associated with a more difficult re-entry.

The nature of the respite service caregivers used for their family member was another factor which influenced re-entry into the caregiving world. For example in one situation, the caregiver realized that a break was needed and reluctantly accepted placement in an institutional respite service for his father. When the caregiver returned from a wonderfully refreshing camping trip, his father

that the respite experience, which had felt so wonderful and free, quickly turned to feelings of guilt and despair.

On the other hand, if the dependent family member was in satisfactory condition upon return, the beneficial effects of the respite experience seem to be enhanced for the caregivers. Similarly, if caregivers felt their dependent family members had enjoyed, or in some way benefitted from the caregiver respite time, they seemed more amenable to subsequent use of respite for themselves.

Implications for Practice

Perhaps the most significant implication of this research for practitioners is the fundamental association of respite service under-utilization with the quality of the caregiver respite experience. The impor-

cult life situations. There must be a strong focus on caregiver-related outcomes rather than on program efficiencies and institutional routines. As well, facilitating caregiver control and choice in determining the specific approach to the respite experience must be central if respite programs are to achieve their desired outcomes of refreshment and renewal.

It also must be recognized that the length and quality of the respite interval influences the degree of caregiver refreshment and ability to cope. Short respite intervals, such as those offered by adult day programming or a few hours of in-home sitter services a few times per week, remain important by providing caregivers with much-needed time for their regular chores of daily living. However, these provide little time for the revitalization needed by caregivers to continue coping in difficult circumstances. It also must be recognized that the benefits of a respite experience are relatively short-lived. Respite programs must be designed to allow for ongoing regularity within extended time periods so the respite break becomes a customary feature in the rhythm of daily life.

Furthermore, clinicians must realize and acknowledge the struggle many caregivers face in giving themselves permission to have a respite experience. By being aware of, and responsive to, this struggle, practitioners may enhance the effectiveness of their interventions aimed at helping caregivers cope with difficult situations. The healthcare system must have social support resources available for respite and these resources must be appropri-

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had deteriorated to the point where he could not return home. For this family, the respite service was inadequate and the conditions in the respite service deficient. In this situation, the quality of the respite interval itself did not have an impact on the re-entry. Rather, the caregiver felt the poor quality of the respite service had been the major contributing factor to his father’s deteriorated condition.

A third factor which influenced re-entry was the condition of the person with dementia at re-entry. A prime example is the previous case. The bitterness and anger of that caregiver reflected poignantly

tance of differentiating between the caregiver experience of respite and services called respite care then follows directly. Clinicians must recognize that it is the caregiver experience of respite that is the intended outcome of respite care services. If caregivers continue to worry about their dependent family members while using a respite service, that service is not respite care.

It is important to recognize that the success of programs intended to provide caregiver respite must be measured by the degree of emotional renewal experienced by the caregivers, and by their ability to continue coping with their diffi-

ate, from the caregivers' perspective, when they are ready for them. Some ways to help caregivers permit themselves to use respite services might include not forcing them into such services before they are ready (while still encouraging them to use such services), helping them find acceptable respite programs, legitimizing the respite services to the dependent family member, and writing prescriptions for respite services.

Finally, practitioners must recognize the direct relationship between the quality of the respite service and the condition of the dependent family member when caregivers resume their caregiving responsibilities. Respite programs cannot be simply custodial in nature; there must be some provision of services which are seen by caregivers as beneficial to their dependent family members. People with dementia, despite their cognitive impairment, must be valued as fellow human beings and regarded with dignity and

respect. Programming environments must be stimulating and include at least minimal therapeutic features. In group, institutional or at-home settings, this could include the facilitation of social interactions, daily walking and/or exercise activities, physiotherapy and meaningful recreational activities. In all circumstances, the programming goal must be the prevention of sudden physical and cognitive deterioration while the care-recipient is in the program. If caregivers link a significant decline in their loved one's functioning to a program inadequacy, they will not be inclined to use that service again.

Conclusions

Because family caregivers are so pivotal in maintaining frail elders with dementia at home, it is critical that the research agenda in this area continue to investigate interventions directed towards enhancing the capacity of family caregivers to care for their family members in their

homes. The following research questions, among others, need to be answered:

- Are there additional factors influencing the caregiver respite experience?
- What is the relationship between length of the respite interval and the caregivers' feelings of freedom and renewal?
- Does the caregiver respite experience facilitate improved relationships between caregivers and their dependent family members?

Finally, there is a need to identify with greater precision those factors which result in negative emotional outcomes for caregivers when they return to their caregiving responsibilities.

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