

Respite as Outcome: Plan it! Do it! Feel it!

“Respite is the period of time when the stress and responsibility is temporarily transferred to a trained provider so one may enjoy that time with peace of mind.”

~ Caregiver Focus Group Participant, 2001



Learning Objectives

1. To explore the meaning of respite from the perspective of caregivers.
2. To understand how our relationships with caregivers can affect their respite outcomes.
3. To enhance our knowledge of ways to support caregivers interjecting moments of respite in every interaction we have with them.
4. To recognize the barriers to respite experienced by caregivers, and strategies to overcome them.

Respite as Outcome

Respite as a concept is not new in caregiver support; however, the Caregiver Best Practice Team explored the evolving definition of respite as outcome, the conditions necessary to support respite for caregivers, and the philosophical framework of respite as a health promoting strategy for caregivers. The Team agrees that respite is one outcome for caregivers. Caregiver satisfaction, service satisfaction, quality of life, maintaining physical and mental health, and increased caregiver knowledge are other outcomes suggested by the Team.

‘Respite as Outcome’ was the major finding of the 1998 National Respite Care Project and had a significant influence on the evolving definition of respite in the *Learning to Listen – Listening to Learn Project*. This report concluded:

- Caregivers, not care receivers, should be the target for respite care programming;

- Respite is not a service but an outcome, resulting from time off from caregiving responsibilities;
- Respite care plans should be based on what people actually need rather than preconceived set of services; and
- Services should be flexible, utilizing a variety of settings, occur in different time slots, and integrate facility-based long-term care, community and volunteer services (Canadian Association for Community Care, 1998).

Defining Respite

The Caregiver Best Practice Team supports the notion that “receiving respite should not be presented as the system filling the gap being created by the (failing) caregiver, but rather as a fundamental right of people who take on the responsibility of caregiving” (Canadian Association for Community Care, 1998).

The following is an overview of the different respite meanings and how they can be integrated in our practice, including a VON Canada definition emerging from the Caregiver Focus Groups (2001). It was noted by the Caregiver Best Practice Team that the

Respite (rĕs'pīt): *n.* an interval of rest or relief; a reprieve; give temporary relief from (pain or care) or to (a sufferer or caregiver)

language of respite might be a barrier for some caregivers. This is not a word often used in their relationships and every day conversations. If we are to understand the concept of respite as outcome, we must first explore the outcomes or meanings of respite as defined by the caregiver.

VON Canada's Respite Definition

During the VON Canada Caregiver Focus Group, caregivers were asked about their meaning of respite, their relationship with providers, and opportunities to experience respite. A new definition of respite emerged in the context of the caregiver-provider relationship and was shared by a participant:

“Respite is the *period of time* when the *stress and responsibility* of caregiving is *temporarily transferred to trained providers* so that one may enjoy that time with *peace of mind.*”

Respite Formula

This definition presents a formula to support providers in creating opportunities for caregivers to experience respite:

$$\begin{aligned}
 &\text{Time + Worry-Free/Guilt-Free Caregiver} \\
 &\quad + \text{“Letting Go” of Responsibility} \\
 &\quad \quad + \text{Sharing the Workload} \\
 &= \text{Positive Respite or “What Respite?”}
 \end{aligned}$$

Many of the caregivers were able to understand the concept that respite is an ‘outcome;’ however, they questioned their opportunities to experience this respite – “What respite?” It was clear respite as an outcome for caregivers is difficult to achieve on an ongoing basis. While having time to focus on oneself, having short breaks from the responsibility, and sharing the workload contributed to caregivers experiencing respite, caregivers still feel primarily responsible, physically, emotionally, and mentally for the care of their family member. The general consensus was they were coping, but would like to have more control over the use of their time to create opportunities to experience respite or ‘peace of mind.’ Therefore, respite is more than just time; it is time to focus on themselves and ‘recharge’ to resume the caregiving responsibilities.

This VON Canada definition supports the “stolen moments” respite meaning presented by Hillman and Chappell (2000), suggesting that in order to experience a break, caregivers must take time away from others. Other meanings of respite include minimizing importance for the need for respite, an angst-free care receiver, relief, a mental and physical break, and connections with family and friends.

Respite as a Health Promoting Activity

The question remains, how do we support injecting moments of respite into caregivers’ lives? Hartrick (1997) supports moving “beyond a service model of care” that addresses problems, to a practice that supports building the capacity of families, that transforms relationships and discovers new meanings in the lives of families. Acton (2002) is one of a few researchers to study caregiver health from a health promotion perspective. She studied the health-promoting self-care strategies used by family caregivers to attend to their own needs. Self-care is “defined as those actions persons take to improve their health, maintain optimal functioning, and increase general well-being” including sleep, eating properly, and exercise (Acton, 2002). Again, the majority of research tends to assume caregiving creates burden and decreases well-being, rather than something that can be simultaneously experienced with well-being (Yates *et al.*, 1999; Chappell and Reid, 2002).

Acton (2002), drawing on the Pender’s health-promotion model, claims that the likelihood of engaging in self-care is influenced by individual characteristics (age,

gender, culture, education, income, and stress levels) and values of certain self-care behaviours (perceived importance of self-care, barriers, and ability to implement self-care strategies). The study concluded that caregivers experience more barriers to experiencing respite and practice fewer self-care behaviours than other non-caregivers. This confirms that many caregivers do not have the time to engage in health-promoting self-care. Those who were able to practice self-care experienced lower levels of stress and the effects of stress on their well-being.

Acton (1997) also found caregivers with more self-esteem and social support were less likely to report the effects of stress. This research supports creating interventions that help caregivers to take care of themselves. Understanding how caregivers take action to promote their own health would support developing programs that would encourage this behaviour. A recent development in Canada, involving the exploration of health-promoting behaviours of caregivers, is a study being conducted by the Canadian Association for Community Care on *Enhancing the Health of Seniors Who Are Family Caregivers Through Physical Activity* (www.cacc-acssc.com).

Plan It! Do It! Feel It!

The VON Canada Caregiver Focus Group participants highlighted that while they were receiving respite services from the Branches, they were not necessarily experiencing respite – a break from the caregiving responsibilities. Building on the respite definition and formula, it is recommended that providers initiate the discussion to support caregiver to Plan It!, Do It!, Feel It! Respite.

It has been recommended that nurses and other providers acknowledge the primary caregiving role of the family, and understand the intimate knowledge of their situation and their needs, so they can help the family to “relinquish the care and take full advantage of the respite time” (Gilmour, 2002). This is tied to the relationship-partnership recommendations. How do caregivers feel about relinquishing responsibility to someone they do not trust or know? Therefore, how do providers support caregivers to experience respite as an outcome?

Strang and Haughey (1999) presents a “three-phase cognitive journey” towards respite or a sense of ‘being free.’ Caregivers achieve respite by

- recognizing the need to get out;
- giving themselves permission to get away; and
- realising the availability and adequacy of social supports to allow them to get away.

They concluded that the quality of respite was more important than the amount of time (Strang and Haughey, 1999). The Caregiver Best Practice Team questioned when and who informed the caregivers about respite. The Team agreed that all providers must support caregivers in respite planning, from the initial contact and as needs change; and, to recognize their needs through

assessments (Treneman *et al.*, 1997), reinforce their needs and give them permission to do respite in a non-judgemental way (Strang and Haughey, 1999).

There are a variety of different models of respite services (Pollock *et al.*, 2001). They vary across five dimensions: purpose, time, setting, activities (Montgomery, 1986), and provider (Pollock *et al.*, 2001). The purpose of respite programs can be primary or secondary respite. Primary respite services focus on relieving the caregiver (for example a care for the caregiver day). Secondary respite is service that meets the needs of the care receiver while providing relief to the caregiver (for example day away programs, summer camps for children, and most home care services).

The Caregiver Focus Group participants acknowledged that having support to provide care through formal home care services was a relief. Respite can also have the purpose of preventing caregiver breakdown and delaying placement of the care receiver in long-term care (Canadian Association for Community Care, 1998; Kosloski and Montgomery, 1995). Whatever the reason, respite should be a part of the menu of services available to individuals and families receiving home care services.

Time of respite is both the duration and the timing of respite. Respite time could be

- a short mental break, having a cup of tea uninterrupted (Teitelman and Watts, 2002), a 'stolen moment' (Hillman and Chappell, 2000);
- a few hours to run errands, meet a friend, have a rest;
- a day or two to visit family away; or
- a week or two for an extended break.

Strang and Haughey (1999) noted it was the quality of the time away, not necessarily the quantity of time, that mattered to caregivers. Therefore, the timing of the respite should meet the needs of the caregiver. If Monday night is bowling night for the caregiver, support should be provided to facilitate going bowling.

The setting of respite varies according to the need and purpose of the respite. It can happen in the home, in the community, or in an institutional setting (Pollock *et al.*, 2001). The caregiver may or may not participate in the program or be present in the home. Out of home options include short stays in facility respite programs, hospitalization, or day away programs (van Beveren and Hetherington, 1995; Strang and Neufeld, 1990).

The fourth dimension of respite is activities. Health-promoting activities like exercise, sleeping, going to meet with friends, going for a haircut, getting a massage, hiring outside help, going to church, taking some time for yourself are all within this dimension (Teitelman and Watts, 2002). The idea is absorbing activities that can give you both a physical and mental break away from caregiving.

The final dimension of provider was not captured by Montgomery (Montgomery, 1986), but helps to describe the models of respite based on who is providing it. Some respite services use paid providers and tend to be more structured and less flexible (Strang and Neufeld, 1990; Gottlieb and Johnson, 2000), while other models of respite services are more cooperative, using the support of extended families, friends, cooperatives, and family to family support (Pollock *et al.*, 2001). Finally, respite does not necessarily need a provider or substitute caregiver. As one of the Caregiver Focus Group participants stated, “you are not the end all and be all of my respite.”

In order for caregiver to feel respite, there are certain conditions that are required to optimize the respite experience. Teitelman and Watts (2002) suggests there are both caregiver specific predispositions and situational conditions. They found that caregivers predisposed to having a sense of fun and humour, self-awareness to the need for respite, a positive attitude, and spiritual beliefs were likely able to experience respite more often. The situational conditions included trusting your care receiver is safe, overcoming resistance to receiving help, and control of their time.

Strang and Haughey (1998) suggests the nature of the pre-illness relationship, the role expectation, the attributes of the respite service, and time influence caregivers from using respite services. They suggest that the length of time in the caregiving role influences their ability to escape from this “caregiving world.” They suggest further that the caregiver’s respite experience is both a cognitive and emotional process with numerous influencing factors including caregiver related factors and situational factors. The cognitive process of respite challenges the notion of respite as a service – something to be offered. Respite as outcome is a less tangible concept than respite as service; therefore, the effectiveness of programs and services should be evaluated according to caregiver outcomes, rather than program policies and procedures (Strang, 2000b). This challenges VON Canada to re-evaluate what we call respite services and respite programs. If they do not provide respite to caregivers as they define it, can we call them respite programs?

Accessing and Assessing Respite

The VON Canada Caregiver Focus Group analysis presents other influencing factors to experiencing respite including several issues identified in this Resource Guide.

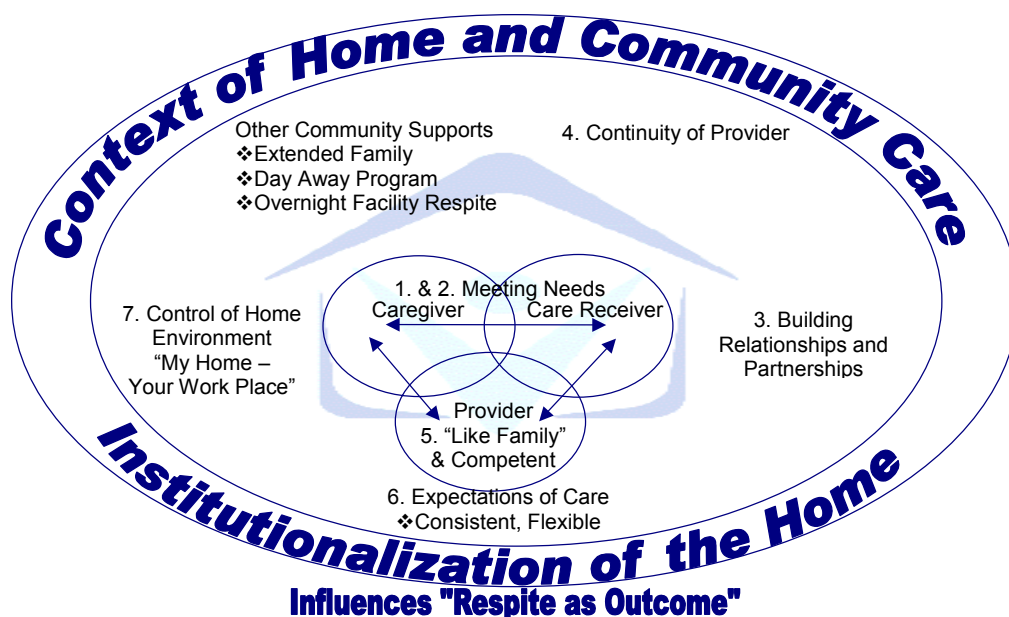


Figure 3: *Influencing Factors for Experiencing Respite* (Schroeder, 2002a)

These factors include:

- Balancing the needs of the caregiver and care receiver;
- Investing in building a relationship and partnership with the caregiver – sharing information, communicating, and working together;
- Feeling the provider knows you – continuity of the provider;
- Having a ‘family like’ relationship with providers and trusting in their ability to do good work (providers with both social and technical skills);
- Having control over their home environment; and
- Having access to supports in services from family and other community supports.

Other influencing factors for caregivers using respite have been presented by Worcester and Hedrick (1997) within the triad relationship between the caregiver, care receiver, and provider.

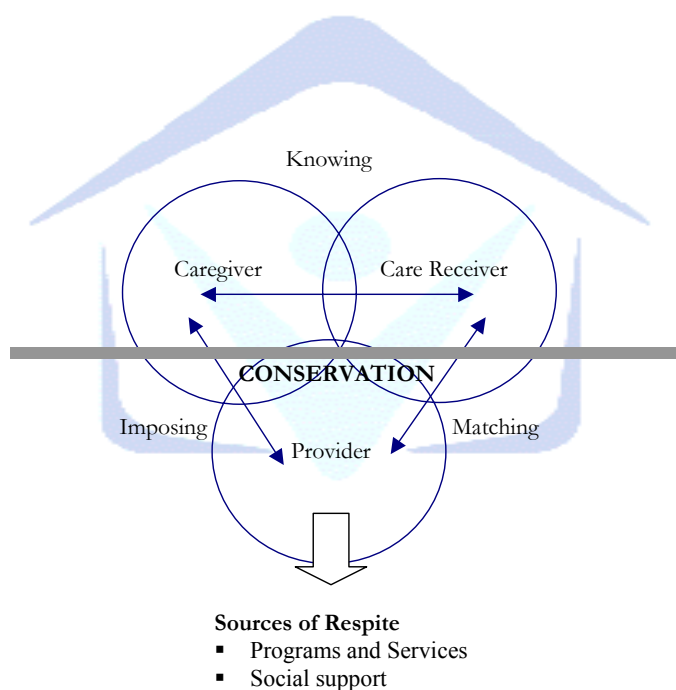


Figure 4: *Dilemmas in using respite* (adapted from Worcester and Hedrick, 1997)

Respite use is influenced by caregivers' ways of *knowing* the care receiver, the feelings of *imposing* on the provider, the *matching* of the care receiver and provider to ensure a good fit. *Conserving* energy and resources of the caregivers is the filter they make decisions about respite use.

Rudin (1994) presents four questions caregivers use to assess and make decisions about accessing respite services:

- Is the service available?
- Is the service accessible?
- What is the quality and hospitality of the service and the setting?
- Is the respite program useful?

This study attempts to answer the reason why respite programs are under-utilized by caregivers. In addition, it recommends a more in-depth exploration of caregivers' choices and preferences regarding respite and the cost of respite utilization (Rudin, 1994).

Respite Barriers

In order to effectively plan for respite, providers need to be aware of the barriers to respite experienced by caregivers as well as the influencing factors. The Canadian Association for Community Care (2002) identified several system barriers to respite including:

- Caregiver angst;
- Lack of knowledge of respite options;
- Insufficient services – in rural communities, emergency respite;
- Insufficient time;
- Unreliable and inconsistent home care services;
- Financial pressures on caregivers;
- Inadequate funding for service providers;
- Lack of culturally sensitive services;
- Restrictive admission criteria; and
- Lack of transportation.

As previously stated, most respite programs do not have the intended effect (Zank and Schacke, 2002). While most caregivers get a physical break away or time for themselves, the emotional and cognitive aspects of respite are not addressed by current respite models (Strang and Haughey, 1999). If there are any positive effects of using respite services, it tends to be short-lived (McNally *et al.*, 1999). It has been suggested that while the respite may provide immediate relief, it does not address the ongoing needs for socially supportive relationships (McNally *et al.*, 1999), control over their use of time (Strang and Haughey, 1998), and control over their home (Schroeder, 2002b). Strang ((2000a)) suggests that we support not only caregivers “getting away” from caregiving responsibilities, but resuming the caregiving and continuing in this role. Therefore, caregivers must be involved in planning the nature of the respite so that it will have the desired impact. Providers must explore the benefits and shortcomings of using respite and the goals of the caregiver for using respite.

A recurring theme in the literature on respite is “choice” (Schroeder, 2002c; Pollock *et al.*, 2001; Treneman *et al.*, 1997). Caregivers want access to a wide variety of options that can meet their own needs, the needs of the care receiver, and the family unit, understanding that their preferences and needs vary between families and across time (Pollock *et al.*, 2001). Caregivers will put the needs of the care receiver as the priority and only access supports and services they feel they can trust. Caregivers need support to plan respite, do respite and feel respite as part of their caregiving role. Programs need to more rigorously evaluate the effectiveness of the services to reflect the caregiver respite outcomes, and determine for whom the outcomes are hindered or facilitated by the policies and procedures. (Pollock *et al.*, 2001; Gaugler and Zarit, 2001). It is clear that respite is an important resource for caregivers. However, the majority of the literature is descriptive in nature and provides little information on how policy makers should set up respite programs. More research on the effect and cost of respite is recommended.

Summary of Key Points

1. Respite is one outcome for caregivers. Caregiver satisfaction, service satisfaction, quality of life, maintaining physical and mental health, and increased caregiver knowledge are other outcomes.
2. “Receiving respite should not be presented as the system filling the gap being created by the (failing) caregiver, but rather as a fundamental right of people who take on the responsibility of caregiving” (Canadian Association for Community Care, 1998).
3. If we are to understand the concept of respite as outcome, we must first explore the outcomes or meanings of respite as defined by the caregiver.
4. “Respite is the period of time when the stress and responsibility of caregiving is temporarily transferred to trained providers so one may enjoy that time with peace of mind.”
5. Respite Formula: Time + Worry-Free/Guilt-Free Caregiver + “Letting Go” of Responsibility + Sharing the Workload = Positive Respite or What Respite?
6. Many of the caregivers were able to understand the concept that respite is an ‘outcome;’ however, they questioned their opportunities to experience this respite – “What respite?”
7. How do we support injecting moments of respite into caregivers’ lives?
8. Hartrick (1997) supports moving “beyond a service model of care” that addresses problems, to a practice that supports building the capacity of families, that transforms relationships and discovers new meanings in the lives of families.
9. The majority of research tends to assume caregiving creates burden and decreases well-being, rather than something that can be simultaneously experienced with well-being (Yates *et al.*, 1999; Chappell and Reid, 2002).
10. Caregivers experience more barriers to experiencing respite and practice fewer self-care behaviours than other non-caregivers. Acton (1997) also found that caregivers with more self-esteem and social support were less likely to report the effects of stress.
11. Building on the respite definition and formula, it is recommended that providers initiate the discussion to support caregivers to Plan It!, Do It!, Feel It! Respite.
12. Respite should be a part of the menu of services available to individuals and families receiving home care services.

13. The quality of the time away, not necessarily the quantity of time, matters to caregivers.
14. While most caregivers get a physical break away or time, the emotional and cognitive aspects of respite are not addressed by current respite models (Strang and Haughey, 1999).
15. Caregivers need support to plan respite, do respite and feel respite as part of their caregiving role.
16. Programs need to more rigorously evaluate the effectiveness of the services to reflect the caregiver respite outcomes, and determine for whom the outcomes are hindered or facilitated by the policies and procedures. (Pollock *et al.*, 2001; Gaugler and Zarit, 2001).



Resources

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Exercise # 10 – Negotiating Respite Role Play

There is tension between you and the caregiver because you think the caregiver should take more respite time, and she feels guilty about leaving her husband. He also resents his wife leaving him alone, which adds to her guilt. The caregiver, who is 60 years old, is run ragged providing 12 hours of care a day, seven days a week. The mutual goal for both caregiver and provider is to ensure that the care receiver's needs are being met.

Enact a role-play in order to negotiate respite so that the outcome is mutually acceptable and satisfactory. The audience (observers) must determine whether the negotiation is done in the form of nurse-helper, worker-worker, manager-worker, or nurse-patient; and, help create a partnership by mediating when necessary. As another option, the observers can critique the quality of communication.



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