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Stolen Moments: Getting a Break When You're A Caregiver

January 2000

Public Report from the Study: "Getting A Break: The Caregiver's Point of View"
Principal Investigators: Neena L. Chappell, Ph.D. and Elizabeth Dow, Ph.D.,

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Centre on Aging, University of Victoria
Victoria, British Columbia CANADA

By:

Lorna Hillman
Executive Director
Family Caregivers' Network Society
526 Michigan Street
Victoria BC V8V 1S2
Tel: (250) 384-0408 / Fax: (250) 361-2600
Email: fcns@pccinternet.com

Neena L. Chappell, Ph.D., FRSC
Director, Centre on Aging
Professor, Department of Sociology
University of Victoria
PO Box 1700 STN CSC
Victoria BC V8W 2Y2
Tel: (250) 721-6369 / Fax: (250) 721-6499
Email: nlc@uvic.ca

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Table of Contents

Executive Summary ii

Stolen Moments, Getting a Break When You're a Caregiver 1

Caregivers for Elders: Who Are They? 2

Table 1 - Selected Demographic Characteristics 3

Table 2 - Social Network Characteristics 5

Elderly Care Recipients: Who are They? 6

Table 3 - Characteristics of Elder Care Recipients 7

Caregiving and Employment 9

Caregiver Burden 11

Table 4 - Caregiver Burden 12

Table 5 - Service Use by Caregivers and Care Receivers 14

The Meaning of Respite: Caregiver Points of View 15

Table 6 - Meanings of Respite 16

Chart 1 17

Conclusion 22

References 26

Executive Summary

The term “respite” means a pause or a rest from a continuous responsibility or activity. The goal of respite services is to enable the caregiver to continue with their responsibilities caring for their loved one at home by preventing over-stress and burn-out. When someone receives a break, this is an outcome. Although “respite” is often viewed as a service, it is actually an outcome experienced by caregivers. **This study sought to re-examine respite, having a break, as an outcome and to understand it from the caregiver’s point of view.** Over two hundred and forty-three caregivers on southern Vancouver Island, those living in the Capital Regional District minus the Gulf Islands, participated in the study.

The dominant meaning of respite for caregivers is referred to as *stolen moments* (48.1%). This is an activity or situation that temporarily takes the caregiver away from caregiving tasks. An activity qualifies as a stolen moment if either (a) the caregiver views it as something which has to be done, i.e., other responsibilities such as grocery shopping; (b) if it is something that may be enjoyable for the caregiver but is part of a regular routine such as watching the evening news or reading for a few moments a day (without specifying that it is either an absolute break from caregiving or some form of intellectual pursuit); and/or, (c) if it is associated with caregiving but provides a change of pace or scenery.

Other meanings include: *minimize the importance of respite* (12%) refers to those who feel a break simply isn’t an issue for them; *angst-free care receivers* (1.2%) refers to caregivers who define a break as occasions when the care receiver is relatively happy/comfortable/angst-free; respite as *a relief* (19%) refers to those who view breaks as a complete mental break away from the care receiver such as a vacation during which the caregiver is out of touch with the care caregiver that these opportunities can be identified. However, caregivers do not focus on themselves, so the system should recognize this and allow workers to take the time to help the caregiver identify their own needs.

The study confirmed that family caregivers and care receivers are minimal users of the community health system. The average number of hours per week services go into the home is 4.6 and the average number of hours the care receiver goes out to services is .9 per week. Caregivers access outside services when the care receiver's condition worsens and becomes more complex.

Caregiving is a burden. However, caregiving for a family member or a close friend is also an act of love and a moral obligation. That is what family and community are all about. **The research confirms that we are a caring society, we have a strong sense of moral obligation and commitment to our most valued relationships.** Burden is a part of life. **This study reveals that it is mainly care receiver problems that are associated with caregiver burden. Specifically, those caring for loved ones with more chronic conditions, worse functional ability, and more behavioural problems are the caregivers who experience the worse burden.**

Stolen Moments:

Getting a Break When You're a Caregiver

Informal caregivers for seniors are both the first resort for care and the predominant source of care, providing between 75-80% of all personal care.[1] With an aging population, and health care reform emphasizing more responsibility by family and community in the care of frail and chronically ill seniors, demand for caregiving will increase. There is concern about the stress and burden experienced by informal caregivers and their subsequent need for a break, for respite.

The term "respite" means a pause or a rest from a continuous responsibility or activity. Respite services are commonly in the form of sitter attendant services through home support services in the home to relieve the caregiver for a few hours or even a few days, or the care recipient is taken out of the home to provide the caregiver with a break by going to an adult day centre or into a short term facility bed for a few days or a few weeks. The goal of respite services is to enable the caregiver to continue with their responsibilities caring for their loved one at home by preventing over-stress and burn-out. Research in this area has not established the effectiveness of these services.[2]

Although "respite" is often viewed as a service, it is more appropriately viewed as an

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[1] Kane, R.L. (1990). Introduction. In R.L. Kane, J.G. Evans, & D. MacFadyen (Eds.), *Improving the health of older people: A world view*. New York: Oxford University Press.

[2] Opie, A., Fulcher, L.C., Hawke, G., & Allen, N. (1992). *There's nobody there: Community care of confused older people.* Philadelphia, PA: University of Pennsylvania Press.

Milne, D., Pitt, I., & Sabin, N. (1993). Evaluation of a career support scheme for elderly people: The importance of 'coping.' *British Journal of Social Work*, 23(2):157-168.

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Over a third (43.2%) live in households that earn at least $50,000 a year. Most caregivers rate their current health status as between good and excellent (79%) and say their self-esteem is high (77.3%).

Table 1

Selected Demographic Characteristics of Caregivers

Where Caregivers Live	**Percent**
Saanich	28.8
Victoria	25.1
Central Saanich	9.5
Oak Bay	8.6
North Saanich	6.2
(All other areas contain <5% each)	

Gender	**Percent**
Male	30.9
Female	69.1

Yearly Incomes	**Percent**
< $20,000	11.1
$20,000 to < $30,000	13.3
$30,000 to < $40,000	15.1
$40,000 to < $50,000	17.3
$50,000 to < $60,000	12.0
$60,000 to < $75,000	19.1
≥ $75,000	12.1

Table 2

Social Network Characteristics of Caregivers

Marital Status	**Percent**
Never married	10.7
Married/common-law	69.5
Widowed	5.8
Divorced/separated	14.0

Living Arrangements	**Percent**
Living alone	20.6
Living with 1 other	42.8
Living with 2 others	16.5
Living with 3 others	11.5
Living with ≥4 others	8.6

Family Members	**Have (%)**	**See closest at least several times/week (%)**
Daughter(s)	65.8	40.6
Son(s)	63.0	38.6
Sister(s)	61.7	7.3
Brother(s)	65.8	6.9
Grandchild(ren)	42.0	11.0

misplace or hide things. Many care receivers sleep excessively during the day, 41.2%; almost half (46.7%) ask the same question over and over; and a third (34.2%) require constant supervision.

Many of the care receivers require assistance with personal care (Table 3), 48.9% need at least some help to take a shower or a bath; and 33.4% need at least some help dressing themselves. Regarding other activities of daily living, 79.7% of care receivers require assistance with shopping; 62.5% need help to prepare their meals; and 47.9% need help to take their medications. The vast majority of care receivers (88.9%) need help to do heavy household cleaning or laundry; and 85.9% need help to do yard work.

Table 3

Characteristics of Elder Care Recipients

Relationship to Caregiver	**Percent**
Mother	38.3
Father	12.8
Husband	11.1
Personal friend	10.7
Wife	7.4
(Other family or family friends are less than 5%)	

Activities of Daily Living	Percent		
	Requires No Help	Needs Some Help	Completely Unable
Able to dress self	66.7	20.6	12.8
Able to get about the house	76.4	13.2	10.3
Able to get in and out of bed	81.1	7.8	11.1
Able to take a shower or bath	50.6	25.9	23.0
Able to use the toilet	81.1	10.3	8.2
Able to use the telephone	68.8	17.4	13.6
Able to go shopping	20.2	38.0	41.7
Able to prepare meals	36.6	26.7	35.8
Able to do heavy housework/laundry	11.1	31.7	57.2
Able to do light housework	99.6	.4	-
Able to do yard work	13.3	21.6	64.3
Able to take own medicine	51.7	26.4	21.5
Able to manage own money (day to day)	53.7	16.9	29.3
Able to handle long term finances	16.3	27.6	55.6

Caregiving and Employment

According to the latest study by the Conference Board of Canada, responsibilities for aging family and friends are taking their toll on Canadian workers and having an impact on their employers. They report that one in four households provide care in some form to an elderly family member or friend. A full 25% of caregivers provide "personal" care - feeding, dressing, bathing - to the person in their care. These people are more likely than other caregivers to report

Caregiver Burden

Much of the literature on caregivers focuses on burden and stress derived from this role. Caregiving is a burden. However, caregiving for a family member or a close friend is also an act of love and a moral obligation. That is what family and community are all about. We are a caring society, we have a strong sense of moral obligation and commitment to our most valued relationships. Burden is a part of life. Motenko, author of the article "Respite Care and Price in Caregiving: The Experience of Six Older Men Caring for their Disabled Wives," writes,

> The closer the bond between the caregiver and the frail elder and the more intimate the care required, the greater the strain in caregiving. In essence, I discovered that caring for their wives is a labour of love for these husbands....motivated in large part by an appreciation of the care and support their wives provided them. In this way the past is part of the present and infuses meaning into caregiving. Caregiving is more than feeding his wife, making sure she takes her pills, cooking, cleaning, shopping, and numerous other daily tasks that this entails. It is an expression of his appreciation and love for her. It is a desire to reciprocate loving care and perpetuate a relationship that continues to hold valuable meaning for him. The guiding principles of love and commitment form the basis of the husband's decision to pursue a lifestyle of caregiving.[6]

Table 4 shows the Zarit Burden Inventory used to ascertain caregiver burden. The majority of caregivers in the Victoria study feel some degree of burden from a little (33.7%) to moderately-extremely (37.5%). When asked if they feel stressed between caregiving and meeting other responsibilities for family or work, 42.0% said sometimes and 23.1% said frequently to always. These conflicting demands can result in feelings of anger and resentment. Caregivers were asked if they feel angry when around the care receiver; 38.3% said sometimes to always. Many feel the care receiver is very dependent on them (79.5%); 49.0% feel strained

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[6] Motenko, A.K. (1988). Respite Care and Pride in Caregiving: The Experience of Six Older Men Caring for their Disabled Wives. In Reinharz and Rowles (Eds.), *Qualitative Gerontology*, pp. 424-428.

	Never	Rarely	Sometimes	Frequently/ Always
Afraid of what the future holds for care receiver	18.9	11.5	34.2	35.0
Feel strained when around care receiver	30.5	20.6	31.7	17.3
Feel your health has suffered because of involvement with care receiver	57.2	17.3	18.5	7.0
Feel that you don't have as much privacy as you would like because of care receiver	52.7	22.2	17.3	7.9
Feel your social life has suffered because you are caring for care receiver	46.9	21.0	21.0	11.1
Feel uncomfortable having friends over because of care receiver (note: 72.2% care receiver not in same household)	12.2	8.3	4.1	2.5
Feel care receiver seems to expect you to care for him/her as if you were the only one s/he could depend on	29.6	13.2	24.7	31.7
Feel you have enough money to care for care receiver in addition to rest of your expenses	72.4	11.1	11.1	5.4
Feel that you won't be able to care for care receiver much longer	51.9	21.0	17.3	9.9
Feel that you have lost control of your life since care receiver's condition	58.8	21.0	14.8	5.3
Wish you could just leave the care of care receiver to someone else	49.2	15.3	23.6	12.0
Feel uncertain about what to do about care receiver	24.3	25.9	36.6	13.2
Feel you could be doing more for care receiver	16.5	15.2	35.8	32.5
Feel you could be doing a better job for caring for care receiver	20.2	22.3	38.8	18.6
Overall, how burdened do you feel in caring for care receiver	Not at all	A Little	Moderately	Quite a bit/Extremely
	28.8	33.7	28.8	5.8/2.9

Even when formal assistance is received, informal caregivers put in the most hours. The National Respite Project reported for all the 19 tasks listed, in every instance, the caregiver is much more likely to provide that care than other family members, friends, or neighbours, volunteers, paid workers, or government. Assistance from all other sources taken together does not come close to the contributions made by informal caregivers. Receipt of government services is low.[7]

When examining caregiver burden, a host of demographic factors such as gender, age, living arrangements, social support factors, and caregiving factors influence the experience. We analyzed the data and found that it is mainly care receiver problems that are associated with caregiver burden. Specifically, those caring for loved ones with more chronic conditions, worse functional ability, and more behavioural problems are the caregivers who experience the worse burden. These are also the care receivers who are more likely to be receiving services and the caregivers who are more likely to be taking breaks. However, there are no differences in this regard between caregivers who are men or women, young or old, married or unmarried. Only the condition of the loved one is burdensome. These findings are shown in Chart 1. Also shown is the fact that burden affects overall well-being of the caregiver, which in turn affects his or her self-esteem.

The Meaning of Respite: Caregiver Points of View

Initially, in-depth qualitative interviews were conducted with 14 caregivers, in addition to a focus group of 5 women caregivers. All focused on what having a break means to them. A preliminary typology of meanings was derived. When the representative sample of 243

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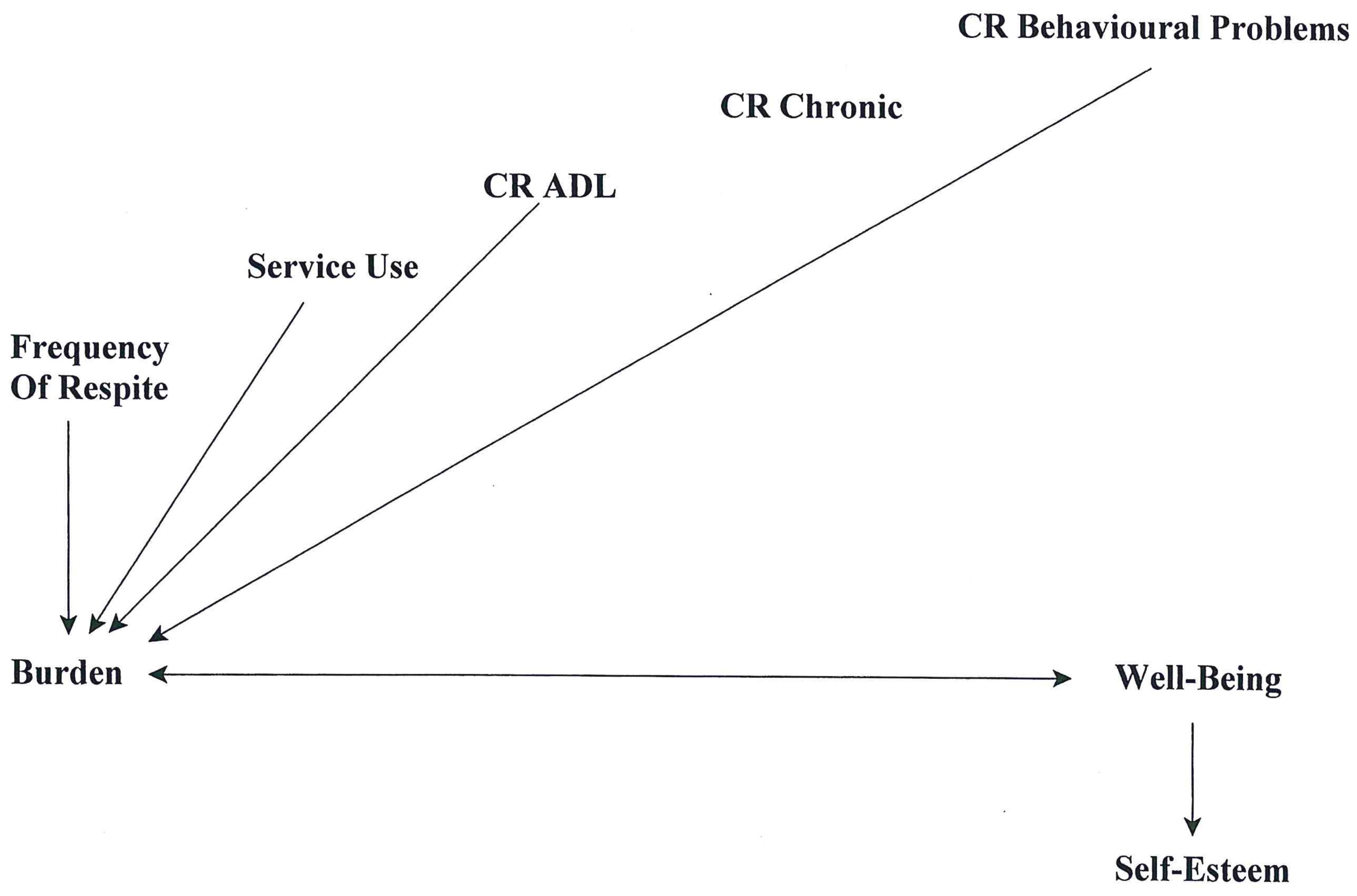
[7] Neena L. Chappell, *Evaluation Report: National Respite Project,* September 1997, p. 8.

Chart 1
Factors Significantly Affecting Caregiver Burden



care receiver. This is distinct from those who obtain respite from a *physical/mental boost or stimulus* (see below) in that the caregiver attains freedom from concern through disengagement of the mind.

Getting respite from a *physical/mental boost or stimulus* (12.0%) refers to situations that engage both the mind and the body in an all-encompassing manner. Comments indicating the positive effects of taking a break on the caregiver's health as well as the detrimental effects of not taking a break are included in this category. Activities which free the caregiver from caregiving responsibilities by engaging the mind in an all-encompassing manner is also included. Some forms of reading or even watching TV qualify as such, as do more intellectual pursuits such as taking a course or pursuing a hobby. Involvement in employment, community or other volunteer activities are also *mental stimulus* breaks, providing the caregiver states them as such (for some, employment is an additional burden and not a break).

Connections (7.5%) refers to social involvement. This category includes making connections with people (the world out there) either in a social sense or as part of a support system such as other caregivers. An individual is placed in this category only if they perceive such contacts as supporting them with a break in and of themselves. For example, going to the movies with friends would only qualify as *connections* if the caregiver specified that the interaction with others, rather than the movie, is what provided them with a break.

It is evident that most caregivers (61%) receive a break in a way many of us would not perceive as a break. Stolen moments can provide minor relief on a temporary basis. Caregiving is work and for many it is arduous work. Providing care for someone with a chronic illness has its ups and downs, which can include acute episodes in the care receiver's condition, a decline in their overall condition, and other family and life situations that arise. Stolen moments suggests exclusively by the health condition and needs of the care receiver. The system has yet to assess caregiver needs systematically.

The fact that having a break means different things to different caregivers suggests that flexibility on the part of the system is essential. Flexibility requires recognition that any service can potentially provide respite for the caregiver and it requires that caregiver needs be acknowledged.

The Evaluation Report, National Respite Project, found that attitudes in the system, such as focussing only on the care receiver and not the caregiver as well, and on eligibility for services rather than need, created barriers to identifying and meeting the needs of caregivers.

> The focus on the caregiver was appreciated by caregivers themselves. The workers on the project stated that the project indicated a much greater need among caregivers than they had been aware of previous to the project. Where there was awareness of caregiver needs before the project, they tended to focus on physical and personal hygiene assistance. In other words, the focus on the caregiver in this project raised the caregiver from an invisible assistant, invisible both to themselves and to the system, where both they and the system focus entirely on the care receiver.[10]

The report on the review of continuing care services in British Columbia, "*Community for Life*" also urges this acknowledgement:

> ...it is also crucial for the Continuing Care system to recognize that caregivers have other important responsibilities: spouses, children, careers, friends, and other relatives. The system should provide real support to help these individuals maintain balance and avoid exhaustion and burn-out.[11]

That is, the system needs to change its attitude about family caregivers by shifting the focus from service eligibility to identifying and meeting their needs to prevent burn-out. Respect for and

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[10] Neena L. Chappell, *Evaluation Report: National Respite Project*, September 1997, p. 17.

[11] Position paper of the Seniors' Advisory Council, *Building Partnerships: Support for Informal Caregivers*, September 1995, p. 4.

in the same household or in an attached apartment. Caregivers feel the most significant meaning of respite for them is *stolen moments*. *Stolen moments* are those opportunities when the caregiver runs errands for the care receiver or themselves; engages in an activity that is still a regular part of the routine but is enjoyed by the care receiver; or is a caregiving activity that provides a change of pace or scenery.

Caregivers are you and me. Although caregiving can be a burden, it is also an act of love and moral obligation. Not only are informal caregivers for seniors both the first resort for care and the predominant source of care, but also the preferred source of care by caregivers and care receivers.

The meanings of respite for caregivers are subtle yet significant and demonstrate the necessity for attitudinal change within the health care system as fundamental to providing flexible, accessible and appropriate services that provide family caregivers with opportunities to get a break. Eligibility criteria that focus only on the care receiver create barriers that prohibit caregiver access to services. If caregivers are part of the assessment for services, it would enable service providers to identify and meet their needs.

Steven Lewis, former CEO of the Health Services Utilization and Research Commission in Saskatchewan, offered some guiding principles to consider when embarking on policy development with regard to family caregivers. He suggested beginning with defining "reasonable expectations" of family caregivers utilizing the "Justice Principle:"

- treat needs equitably;
- do not exploit just because you can;
- recognize caregiver needs as much as care recipient needs;
- develop a coherent policy on public/private responsibility;
- self-reliance should not mean servitude;
- society is interested in cost minimization;

need to make existing services more accessible to the caregiver. Because services provide the possibility of a break, it is only through discussion with the caregiver that the nature and timing of these opportunities can be identified. Therefore, it is essential that the system conduct an assessment of caregivers to have their needs identified and addressed. However, knowing that caregivers do not tend to focus on themselves, the system should recognize this and allow workers to take the time to help the caregiver identify their own needs.

Caregivers are essential to the health care system. We must find ways to work with them as partners in care.

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