

HBRP | Healthy Balance
Research Program

A community alliance for health research
on women's unpaid caregiving.

Caregiver Resilience and the Quest for Balance

A Report on Findings from Focus Groups

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A Report on Findings from Focus Groups

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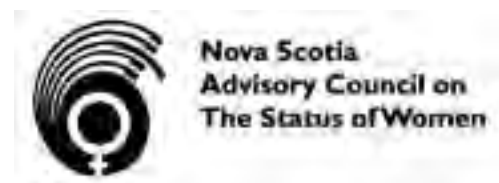




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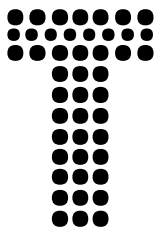
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Preface

Given that thousands of Canadians, the majority of whom are women, serve as unpaid care providers to children and the elderly, there is an urgent need to understand the interplay among the determinants of health and how these factors affect the well-being of caregivers,



The Healthy Balance Research Program is a five year exploration of the relationships between women's health and well-being and their paid and unpaid work. Funded by the Canadian Institutes of Health Research as part of its Community Alliance for Health Research funding stream, the program is co-sponsored by the Atlantic Centre of Excellence for Women's Health, Dalhousie University, and the Nova Scotia Advisory Council on the Status of Women. The work is supported by an extensive network of academic, government and community partners.

The program of research examines normative unpaid caregiving work throughout the life course, including the provision of care to children, teenagers and adults of all ages. Our definition of caregiving expands upon conventional descriptors in the health literature by encompassing a sense of control, economic gender equality indicators and the health status of caregivers.

Given that thousands of Canadians, the majority of whom are women, serve as unpaid care providers to children and the elderly, there is an urgent need to understand the interplay among the determinants of health and how these factors affect the well-being of caregivers, both positively and negatively. In addition, it is important that we recognize how the determinants of health, and the over-riding social values and expectations, shape social trends and attendant public policies.

Four research teams are exploring different aspects of these issues, using methodologies designed to highlight varying facets of the caregiving experience.

- Secondary analysis of existing data on caregiving, such as the General Social Survey, Cycle 12, to deepen our understanding of the stress reported by employed women

who also provide unpaid care and of the realities that underpin the reported hours of paid and unpaid work

- Focus groups of caregivers around the province of Nova Scotia organized to include different communities and different caregiving situations
- A population-based survey of Nova Scotians to gather data on numbers of caregivers and to explore relationships and empowerment
- Caregiver portraits, micro-ethnographies of fourteen diverse households in which a caregiver is providing substantial care either for someone in the household or for some other relative or friend.

Healthy Balance has a strong focus on the process of doing research with such a multiplicity of partners. Process elements include:

- research teams bring together researchers from several universities with diverse and complementary expertise
- Equity Reference Groups provide an opportunity to interact directly with members of the communities they represent
- partnerships with agencies in the community create avenues for productive exchange
- a National Reference Group of academics and policy-makers serves as a sounding board and advises on ways to have an impact on policy
- a post-doctoral researcher develops a research program and contributes to the integration of all research findings
- a scholarship program supports graduate students and welcomes them as beginning researchers
- participants keep in touch in various ways, including joint meetings, to reinforce our shared vision of and commitment to the Healthy Balance work

This report presents the findings of the focus group research. Other reports will follow as the Healthy Balance research continues. Taken together, all of the findings from the

various strands of research will enrich our understanding of the caregiving experience and will point to steps required to build supportive communities.

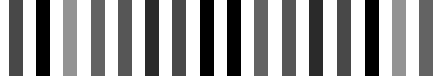
We are delighted to share this report with you. We thank the Team Q researchers - Jacqueline Gahagan, Charlotte Loppie, Marlene MacLellan, Laurene Rehman and Katherine Side - for their commitment and their thoughtful approach to planning, conducting and analyzing the focus groups. Their contribution is an important building block in our efforts to understand the health and well-being of women who juggle unpaid family responsibilities with paid employment.

Our hope is that this report generates discussion and crystallizes creative action directed towards caring communities supportive of caregivers and care receivers alike.

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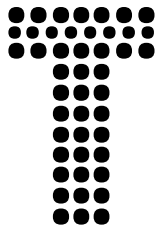


Executive Summary

The Healthy Balance Research Program is a five year exploration of the relationships between women's health and well-being and their paid and unpaid work.



Introduction



The Healthy Balance Research Program is a five year exploration of the relationships between women's health and well-being and their paid and unpaid work. Funded by the Canadian Institutes of Health Research as part of its Community Alliance for Health Research funding stream, the program is co-sponsored by the Atlantic Centre of Excellence for Women's Health, Dalhousie University, and the Nova Scotia Advisory Council on the Status of Women. The work is supported by an extensive network of academic, government and community partners.

The program of research examines normative unpaid caregiving work throughout the life course, including the provision of care to children, teenagers and adults of all ages. Our definition of caregiving expands upon conventional descriptors in the health literature by encompassing a sense of control, economic gender equality indicators and the health status of caregivers.

Team Q Development and Research Methodology

A multi-dimensional network of partners is conducting the HBRP research in four teams: the Focus Group Team (Team Q), Caregiver Portraits Team, the Population-based Survey Team and the Secondary Data Analysis Team. The work of Team Q included conducting focus group discussions with caregivers from different communities and caregiving situations across Nova Scotia. The data collected from the focus groups identified many of the differences and similarities between various caregiving situations, and provided important information about the impact of caregiving on work, family, health and well-being. The inclusion of diverse groups provided rich data on the role that diverse life circumstances play in the caregiving

experience.

The Healthy Balance Research Program is committed to ensuring that women who are often under-represented in research are included in a meaningful way. Four Equity Reference Groups (ERGs) - African-Canadian women, First Nations women, immigrant women, and women with disabilities - were established in order to fulfill this commitment. ERG members provided valuable input into the details of the focus group research process. They made recommendations on the development and use of culturally appropriate and respectful data collection methods, including feedback on recruitment issues and potential focus group facilitators, and contributed information sharing strategies in their communities. They have also committed to facilitating the translation of research into better policy and practice.

A focus group discussion guide was developed through drawing upon an extensive literature review and in consultation with members of Team Q and the ERGs. The objective of the series of questions used was to gain a better understanding of the relationship between unpaid caregiving, empowerment and health status, to further explicate "useful practices" in caregiver policies, programs and supports, and to gain additional insights into new or innovative approaches to caregiving and health promotion.

One of the key goals of the Healthy Balance Research Program is the enhancement of research skills and capacity at the community level. To this end, and to help increase the level of comfort of those participating in the focus groups, facilitators were selected from specific communities across the province. A Focus Group Coordinator was engaged to assist facilitators in locating participants, coordinate the logistical arrangements, prepare materials, attend the focus groups and prepare a report.

The focus groups provided an opportunity for

caregivers from a variety of communities to identify with other individuals with similar experiences and, as such, were in keeping with the goal of the Healthy Balance Research Program: to help build community.

Who Are the Caregivers?

The caregivers who participated in focus group discussions for the Healthy Balance Program represent a diverse group of 98 women and nine men from across Nova Scotia. These caregivers ranged in age from 17 to 85, with an average, or mean, age of 45 years; their annual family income ranged from less than \$20,000 to more than \$50,000. Participants make their homes in diverse communities within several regions of Nova Scotia. In particular, the geographic categories represented in this sample include rural communities (33), villages (4), towns (33), and cities (31), as well as other geographic categories (6). Participants also represented a variety of ethno-cultural groups, including First Nation peoples (on and off reserve) (15), African Canadians (16), Euro-Canadians (49), new Canadians (13) and Others (14). Twenty-three (23) of the participants also identified themselves as individuals with a disability.

Participants had different reasons for becoming caregivers and a wide variety of situations shaped their caregiving experiences. Four main themes characterizing these experiences are professional roles, personal skills and qualities, gender and race, and family dynamics.

The Additional Work of Caregiving

Caregiving is much more than simply attending to the physical needs of a recipient. Caregivers have multiple roles and responsibilities, including advocating on behalf of themselves and the recipients, ensuring that recipients are treated with respect and dignity, and that as far as possible, recipients have input into decisions concerning their care. They also have to take care of themselves so they can continue providing care to others. All these roles and

responsibilities have to be carefully balanced. Caregivers had little time for self and frequently experienced fatigue, stress, and other similar health concerns.

The Impacts of Caregiving

Caregiving had an impact on the health, work and leisure, and the need for adequate transportation and finances, in the caregivers' and the recipients' lives.

Participants social lives underwent severe changes due to the tremendous additional workload of providing care. Their social lives were affected as the inability to maintain social networks increased and friendships declined.

The caregivers also experienced a number of emotional, mental, or cognitive impacts on their health. Some of these were related to the stress associated with caring and its resultant physical impact upon the body. Caregiving also affected the physical health of the participants. They frequently identified exhaustion and loss of stamina and strength related to provision of care. In addition, caregiving sometimes resulted in physical injury to the caregiver due to the large amount of heavy lifting.

Part of the health impacts caregivers experienced may have been influenced by their nutrition and diet. Many felt they were eating poorly both in quality and quantity due to time constraints resulting from the multitude of caring responsibilities.

Work and leisure were two commonly identified life spheres which participants found had direct impacts on their ability to provide care. Work was only discussed by participants engaged in paid employment. Those who did not engage in paid employment did not label caregiving and unpaid labour responsibilities as "work". For many of the participants, paid employment was a financial necessity. They were required to balance their paid employment along with their caregiving roles and responsibilities in



order to meet financial obligations. A number of challenges arose as a result of this balancing of multiple work responsibilities

Giving up leisure to take up caregiving was quite common. Leisure was very important to the participants but constraints hampered their participation and enjoyment. Priorities were given to paid employment and unpaid caregiving.

Transportation issues had a direct impact on the caregiving experience and were also affected by it. Although there were many additional financial concerns not specifically related to transportation, access to appropriate and adequate transportation was intricately linked with income and affordability.

Beyond transportation-related financial concerns, a number of other expenses were identified by participants as having an impact on their caregiving. These costs included alternative care provision, care recipient expenses (e.g., ambulance when out of the province, special diets), clothing, housing, and extras (e.g., eating at McDonald's). Participants felt that, when providing care, their costs seemed to quickly escalate and the basic daily living expenses were further compounded by additional costs if the care recipient required special care.

Two frequently identified daily living expenses which were a challenge for caregivers in this study were housing and alternative care.

Caring for the Caregiver: Personal and Community Networks

Participants included self-care and the support from family, friends and the community as key elements of care for the caregiver.

Caregivers identified a number of self-care and coping strategies, including having supportive relationships and making time for humour, spirituality and leisure, that they used to

facilitate their ability to provide care. These strategies allowed the caregiver to handle or reduce some of the challenges they might otherwise face in their day-to-day lives. Some were performed on their own behalf, while others were done more specifically for the care recipient.

The stress of caregiving was seldom experienced in isolation. Individual caregivers and care recipients were often members of kinship networks that they relied on for support in their caregiver role. Family members, such as parents, siblings, close relatives, and elder children, were often affected by the supports they provided. It had a "ripple" effect by enhancing the health and well-being within the family. Trusted friends, neighbours, and teachers create the another circle of support.

Some caregivers "traded care" with each other as a form of barter, which provided both with much-needed support, while minimizing emotional costs associated with asking for help from family and friends.

Participants experienced stress, loneliness and depression. Many caregivers claimed that emotional support in the form of empathy, appreciation and commiseration, was an essential element of supportive relationships. Caregivers described their need for non-caregivers to identify with some of the difficulties that caregivers were experiencing. They wanted others to understand the significance of the caregiver's role, not only in the care recipient's life, but also in the lives of those who would benefit indirectly through diminished caregiving responsibilities. Commiseration appeared to be a major component of reciprocal support among caregivers, whether in the context of a formal support groups or individual relationships.

The way that caregivers sought support and resources was affected by the relationship they had with family and friends. Historic family hierarchies, power imbalances, and

past disagreements over the provision of care underscored the dynamics within which support was sought and received. Caregivers feared that the support they received would not be of the kind they wanted, and soliciting help often entailed submitting to intrusions that they did not consider appropriate.

Although caregivers were somewhat reluctant to discuss this negative aspect of support, they did describe the way that people offering support sometimes imposed unwanted changes to well-established routines and gave unsolicited advice about the appropriate manner in which they should be providing care. This influenced the comfort with which caregivers received and subsequently sought further support, but they felt that rejection of this unwanted “help” or advice was tantamount to “biting the hand that feeds them”; a position few weary caregivers were willing to assume.

Despite the large number of challenges they faced, many participants talked about the rewards of caregiving. It was often the rewards that helped the caregiver negotiate the challenges. Participants described one such reward as simply feeling good about themselves because caregiving enabled the caregivers to feel they had contributed something worthwhile despite facing challenging situations and, therefore, to experience a sense of satisfaction and enjoyment. The other predominant reward associated with caring was the education the caregiver obtained. This education was in two areas: learning about the health care system and caregiving, and learning about their own emotions. Most of the learning described by caregivers was in relation to their emotional and spiritual growth.

Organizational Resources

Participants described physicians, home care workers, Victorian Order of Nurses (VON) workers, hospital staff, support groups, church/spiritual groups and employers as members of a

more formal support network with whom they had regular or intimate contact and/or a more intimate physical or inter-personal relationship. Allied health professionals, workshops, and various community organizations with whom caregivers had less direct or prolonged contact and/or who provide less personalized support were also named as supports.

Formal supports provided a relatively objective context within which caregivers could express their concerns and problems without fear of creating tension that might lead to inter-personal conflict; however, participants pointed out that individuals outside the caregivers’ informal network may not fully appreciate the subjective impact of caregiving, and formal support was often limited to supports related directly to addressing care recipient needs.

Caregivers cited information resources as a major source of formal support. In particular, print material and the internet provided useful information about specific conditions that affected care recipients. Informational resources enhanced caregivers’ abilities to cope with the uncertainty they experienced around caring for someone who was very ill. Information also improved the caregivers’ capacity to provide care and expand the knowledge of those within the caregiver’s support network.

There were a variety of other resources which were identified as being supportive by focusing on skills development for caregivers, providing medical or practical assistance, serving as advocates and attending to psychosocial needs.

Social implications of accessing resources were identified. Some occurred in personal contexts which involve coping or adjustment on the part of the caregiver in order to access resources. Ironically, in-home and respite care represented a source of stress for caregivers because it involved giving up control and trusting a stranger to care for a loved one. Moreover,



caregivers often had little control over when care was provided, and this limited the benefit of in-home support. Participants reported that in-home care can be intrusive, and that it is especially important for home care workers and caregivers to work closely in coordinating the care so that it is not disruptive to the care recipient, the caregiver, or to informal support networks. A relational context is also apparent. Participants acknowledged the importance of maintaining good relationships with those who are in positions of power in order to access the resources they required. Caregivers often walked an interpersonal tightrope of diplomacy held together with a healthy measure of humility in order to secure resources for themselves, their families and/or their care recipient.

Caregivers living in small or rural communities had to consider issues of privacy and confidentiality when members of the immediate community provided in-home care. In addition to their immediate responsibilities for providing care, caregivers also had to adopt administrative roles that were sometimes hindered by resource bureaucracies. While these activities did not always tax financial resources, they required the caregiver's time, something most found in very short supply. The added stress of these organizational and managerial responsibilities reduced some caregivers' capacity to effectively access resources. In fact, participants reported that the necessity for extensive planning and rigid compliance with resource-related procedures effectively prevented them from accessing certain supports.

Barriers and Gaps in Support

A lack of awareness about what programs and services were available presented a barrier to accessing services. This lack was compounded by the isolation many caregivers experienced due in part to financial, social and economic circumstances. Financial barriers were especially relevant for caregivers who required in-home and/or respite care. Paid care provided

a measure of control, while inadequate financial resources not only undermined caregivers' control over what resources were available but also the degree to which caregivers controlled when and how those resources were provided.

Although few caregivers refused support when it was offered, most acknowledged that the degree to which they benefitted from that support was also constrained by time, resources, and geography. This became so burdensome to negotiate that caregivers often did not seek support.

Women caregivers reported feeling unsupported because of inequitable and unchallenged gender expectations. This gap exists within both formal and informal support networks and is rooted in beliefs about the relative value of male and female caregiving, and the extent to which caregiving falls within socially constructed gender roles.

Lack of support frequently led to health consequences for caregivers; these had a ripple effect on individuals, families and communities. From physical illness and injury to isolation, helplessness and depression, deficiencies in one area of support tend to leak out into other domains.

The Equity Reference Groups' Caregiving Experiences

Focus groups were organized in the communities of the Equity Reference Groups - Aboriginal women, African Canadian women, immigrants, and women with disabilities. These discussions reinforced the reality of some common, shared caregiving experiences across cultures while highlighting unique experiences within each group. This is important because the caregiving experience of ERGs are often poorly understood in the broader caregiving literature. Aboriginal women, African Canadian women, immigrant women, and women with disabilities may have differential access to resources, which results

in challenges, such as not owning a vehicle or not having the resources to buy extra helpful equipment or respite care. They may also face challenges advocating on behalf of caregivers and recipients in attaining government health services.

Discussion

Through the voices of those participating in focus group discussions, this report documents the various situations and experiences of selected groups of individual caregivers in Nova Scotia. Caregiving experiences ranged from the realm of what may be identified as “normative” family interactions and responsibilities, to the provision of complex nursing care. The fact that a single definition of caregiving did not emerge is both a strength and a limitation. What did emerge was an extensive overview of the diversity of caregiving with its multiple meanings and expressions. The strength lies in the breadth of situations that illustrate the caring face of our society. The limitation lies in the fact that such a multitude of care provision manifestations makes it difficult to offer simple policy responses to fit such diversity.

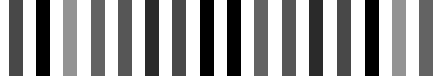
Caregiving is as varied as the relationship within which it occurs. Our individual perspectives frame caregiving, as do culture, personal expectations, public policies and values. At the conclusion of this report we return to the beginning of the Healthy Balance Research Program, where Armstrong and Armstrong (2001) emphasized that caregiving should not be construed as a “social problem”. Caring for each other is a defining human trait and what society is ultimately for. We need to build a society with caregiving as a central value.

Recommendations

1. Policies, programs and practices need to take into account the situation of specific caregivers. At a time when there are many different family forms, greater diversity in

communities, varying resources in urban and rural settings—it is clear that a “one size fits all” approach will not provide for a situation where caregivers are adequately supported, the caregiving relationship is fostered, and the negative social, health and economic consequences of caregiving are mitigated.

2. Women remain the dominant source of caregiving in our society. While many men too participate in various aspects of caregiving, time use studies consistently demonstrate that women predominate both in the frequency with which they give care, and the quantity of care they provide. Furthermore, different cultural groups require interventions sensitive to their needs. Finally, the accommodations needed by caregivers with disabilities should be specifically defined and provided.
3. For caregivers in the paid workforce, employment policies to accommodate caregiving need expansion and better application in both large and small business sectors.
4. Caregivers need supportive communities, with both physical and social infrastructure required.

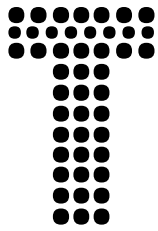


Chapter 1: Introduction

Caregiving today is conducted in the context of globalization, with its increased emphasis on markets and rapid social change, such as improved living conditions, an aging population, and conditions such as Alzheimer Disease and HIV/AIDS. (Armstrong and Armstrong, 2001.)



The Healthy Balance Research Program



This report is a part of the Healthy Balance Research Program (HBRP). The Program was established in 2001 to explore:

- the impact of caregiving on women's health;
- the rewards of caregiving;
- the demands caregiving places on family life;
- and the relationship between unpaid caregiving and paid employment.

In this research, 'caregiving' is defined as unpaid caregiving work throughout the life course, including the provision of care to children, teenagers and adults of all ages. This definition of caregiving expands upon conventional descriptors in the health literature which limit caregiving to caring for vulnerable persons. Research participants were included based on their own self-identification as caregivers.

One goal of the HBRP is to provide the data needed to help foster a healthy balance between women's health and well-being and their paid and unpaid work. A secondary goal is to use the data to improve our understanding of the ways in which caregiving is now organized, how caregiving affects people's sense of control in their lives, and, in turn, how that affects their well-being. It is anticipated that the dissemination of this novel understanding will result in the uptake of new ideas and practices in policies and in programs, and as a result, health service delivery will reflect new insights into the values and expectations brought to caregiving and paid work.

Caregiving in Nova Scotia

Caregiving today is conducted in the context of globalization, with its increased emphasis on markets and rapid social change, such as

improved living conditions, an aging population, and conditions such as Alzheimer Disease and HIV/AIDS. (Armstrong and Armstrong, 2001.) It is also a time when "our evolving health care delivery system sends hospitalized patients home sooner and sicker" (Hoffmann, 2002, p. 1). Although "support for those needing care has long been recognised as a collective and public responsibility," there is strong evidence indicating that it is the family, broadly defined, that is burdened with the responsibility for care (Armstrong and Kits, 2001, p. 28). In fact, according to Hoffman, family members are expected "to provide many functions previously considered to be nursing" (Hoffmann, 2002, p.1).

Traditionally, research explored the growth, nature and economic aspects of caregiving; consequently, there is a dearth of literature focusing on the psychosocial needs of caregivers and the significance of the age, gender, race/ethnicity, marital status, income and employment status of both the caregiver and the recipient (Hoffmann, 2002). While the challenges and rewards of caregiving are shared by most caregivers, there are differences among caregivers depending on their economic, social, political, racial, cultural and physical locations (Armstrong, 2001). The HBRP research recognizes that caregiving is a complex and multi-faceted role, and there is a need for exploration of the context and attitudes around caregiving, the impact of the work, and the need for caregivers to receive support (Lane et al, 20003).

A Report entitled Self-Awareness in Family Caregiving lists the many needs of caregivers:

- information, support, access to services and resources;
- understanding and cooperation from employers, family members, friends and neighbours, health care providers, health plan administrators, their own physicians,

and even strangers;

- new skills – communications skills, financial management skills, time-management/organizational skills, even medical-technical skills;
- financial assistance to help with non-compensated costs for incidentals, transportation, respite care, home modifications, medical supplies, equipment and medicines;
- someone to talk to and share experiences with;
- someone to do an errand;
- a place to go for a change of environment and fresh perspectives.

(Hoffmann, 2002, p.2).

The contents of the Report

This report begins with details about the research team development and methodology. It then documents the perceptions of caregivers in Nova Scotia. Chapter Three: Who are the caregivers? describes the background of the caregivers who participated in the research, their skills and qualities, gender and race, and the family dynamics within which they provide support. Gender was one of the most frequently identified factors in caregiving. Caregivers recognize that caregiving is assumed to be women's work, and work that is not valued highly in today's society. This assessment reflects that found in the literature. "Care work is women's work...It is often invisible, usually accorded little value and only sometimes recognized as skilled" (Armstrong and Armstrong, 2001, p.2). The universal reality that the work is unpaid, is indicative of the lack of value accorded to it (Morris, 2002) in contrast to paid work, which is seen as 'productive' (Lister, 2002, p. 521).

Caregiving is not simply a matter of providing care for a care recipient. Chapter Four, the Additional Work of Caregiving describes how participants balance their multiple roles and responsibilities to ensure that appropriate care is provided for the care recipient and that role

models exist for future caregivers. Chapter Four explores advocacy as an important component of caregiving work. This chapter documents caregivers' work to ensure the recipients of care have a voice in their care and retain their dignity.

Chapter Five, The Impacts of Caregiving, explores participants' perceptions of how caregiving affects a number of aspects of their lives, including their health, their paid employment and their leisure, their ability to travel within their communities, and their abilities to afford both daily living expenses and the extra costs associated with caring. Yet, despite the large number of challenges and often negative impacts of caregiving, caregivers do experience feelings of accomplishment, learning, and personal growth. The rewards of caregiving are explored in depth in Chapter Six.

Perhaps the most important question answered in this report is, "Who cares for the caregiver?" The literature is clear: support, including the support of family, friends and the community, is a "fundamental coping resource" (Elloy and Mackie, 2002, p. 909). Participants in this study provided a wealth of information about the social implications of accessing caregiver resources within specific personal, family and social domains. Caregivers recognize the impact of dignity, respect, and understanding on the care recipients, regardless of whether in activities of daily living or in palliative care, and they work hard to achieve it. Caregiving is not simply a set of actions but rather it consists of a complex web of social relationships, and perhaps the most critical constituent of this is how caregivers access practical and emotional supports that assist them to cope. Chapter Six, Caring for the Caregiver: Personal and Community Networks, details how caregivers care for themselves, request and receive the support of family, friends and their communities so they can be strong enough to continue the work. Proximity and culture, caregiver



expectations, and relationship dynamics are also discussed in Chapter Six.

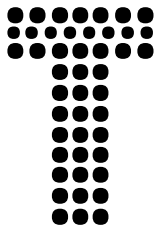
In order to provide a high standard of care, caregivers learn how to manoeuvre through complex systems of often inadequate organizational supports. The resources available to caregivers, their difficulties accessing them, and gaps in services are discussed in Chapter Seven, Organizational Resources. Chapter Eight focuses on the barriers and gaps in supports. Some women face more barriers than others, while some have more cultural supports. Chapter Nine, Caregiving Experiences in the Equity Reference Group Communities, is an in-depth look at caregiving in Aboriginal, African Nova Scotian and immigrant communities, among caregivers with disabilities.

The report ends with a discussion of the findings of the research and recommendations for further action in Chapter Ten.



Chapter 2: Team Development and Research Methodology

The work of Team Q included conducting focus group discussions with caregivers from different communities and caregiving situations across Nova Scotia.



The methodology used in this research reflects protocols for qualitative research. Particular attention was paid to the need for data to reflect the diversity of caregivers in Nova Scotia.

Team Development

A multi-dimensional network of partners is conducting the HBRP research in four teams: the Focus Group Team (Team Q), Caregiver Portraits Team, the Population-based Survey Team and the Secondary Data Analysis Team. (See Appendix A for a brief description of the research teams.) The Population-based Survey Team and the Secondary Data Analysis Team are responsible for the quantitative research used in the study. The qualitative research was conducted by the Focus Group Team (Team Q), which was responsible for Phase One of the Program. Team leaders met regularly throughout the project.

The work of Team Q included conducting focus group discussions with caregivers from different communities and caregiving situations across Nova Scotia. The data collected from the focus groups identified many of the differences and similarities between various caregiving situations, and provided important information about the impact of caregiving on work, family, health and well-being. The inclusion of diverse groups provided rich data on the role that culture and disability play in the caregiving experience. The data from these focus groups will be used to identify relevant issues and has informed the development of the population survey in Phase 2 of the research.

Team Q consisted of six core members, all with strong backgrounds in qualitative research methods, women's health research and/or caregiving research. Throughout the process, they regularly held face-to-face meetings. Team Q members met regularly. In addition, members provided their expertise in data

collection methods, data analysis and report writing for updates and to discuss each phase of the process. Team Q members met regularly. Team Q members met with the Equity Reference Groups (ERG) and National Reference Group (NRG) to discuss the focus group process and to seek advice on how best to proceed in a culturally appropriate manner.

The Equity Reference Groups (ERGs)

The Healthy Balance Research Program is committed to the inclusion of historically disadvantaged and under-represented groups. To ensure that the overall program of research achieves that goal, four ERGs, including African-Canadian women, First Nations women, immigrant women, and women with disabilities, were established. (See Appendix B for the terms of reference for the Equity Reference Groups.)

To facilitate the active inclusion of more socially marginalized groups, an ongoing partnership was developed between the ERG members and Team Q. The ERGs provided valuable input into the details of the focus group research process. They provided recommendations on the development and use of culturally appropriate and respectful data collection methods, including feedback on recruitment issues and potential focus group facilitators, and contributed information sharing strategies in their communities. They have also committed to facilitating the translation of research into better policy and practice.

Research Ethics

The research proposal for this project was approved by the Dalhousie University's Research Ethics Board on December 1, 2001.

Instrument Development

A focus group discussion guide was developed through drawing upon an extensive literature

review and in consultation with members of Team Q and the ERGs. The objective of the series of questions used was to gain a better understanding of the relationship between unpaid caregiving, empowerment and health status, to further explicate useful practices in caregiver policies, programs and supports, and to gain additional insights into new or innovative approaches to caregiving and health promotion. Based on feedback from both Team Q and the ERGs, as well as the findings from the pilot focus group, some questions were reordered or reworded and follow-up questions, or probes, were added to assist facilitators in generating open discussion among participants. (See Appendix C for the Focus Group Discussion Guide.)

The revised focus group guide was used with the remaining 18 focus groups. Although the guide was altered to provide greater clarity, not every focus group required use of any or all of the probes.

Sampling Design

In consultation with ERGs the focus on including particular groups became an important consideration in the sampling design. This was a change from the initial sampling design discussed by members of Team Q, which involved conducting focus group discussions in each of the nine provincial health districts to ensure sufficient participation from both rural and urban caregivers. Although this regional approach was not used due to its lack of appropriateness in achieving the sampling objectives, focus groups were conducted throughout the province. The end result was that groups were organized to capture distinct realities. Eight groups reflected membership in one of the designated equity communities (two African Nova Scotian; two Aboriginal [on-reserve, off reserve]; two from the disability community; two from the immigrant community). Two groups were organized for low-income women and one group for rural

women. The remaining seven groups reflected particular kinds of caregiving experience (lone parents, caregivers for persons with HIV/AIDS, caregivers for elderly persons, caregivers for children with disabilities, caregivers who are themselves elderly, caregivers of adults with disabilities, male caregivers).

Recruitment

Based on feedback from the ERGs and Team Q members, it was felt that recruitment within the various communities would be better accomplished by collaborating with a member of each community to recruit participants and facilitate the focus group discussions within their respective communities. Team Q researchers were present at some of the focus groups.

Connecting to the Community

One of the key goals of the Healthy Balance Research Program is the enhancement of research skills and capacity at the community level. To this end, and to help increase the level of comfort of those participating in the focus group, focus group facilitators were selected from specific communities across the province. Three of the facilitators had no previous experience conducting focus group discussions. A Focus Group Coordinator was engaged to assist facilitators in locating participants, coordinate the logistical arrangements, prepare materials, attend the focus groups and prepare a report.

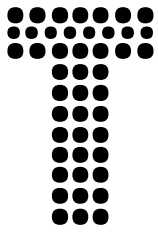
The focus groups also provided an opportunity for caregivers from a variety of communities to identify with other individuals with similar experiences and, as such, were in keeping with the goal of the Healthy Balance Research Program: to help build community.





Chapter 3: Who Are the caregivers?

“I think women just assume the responsibility. Years ago we weren’t expecting to go to college or have a career. We were mostly at home and being mothers. Myself, I still have to shake my head to get that out...I take responsibility. I think women assume responsibility without even being asked. Women get the job done.”



The caregivers who participated in focus group discussions for the Healthy Balance Program represent a diverse group of 98 women and nine men from across Nova Scotia. These caregivers ranged in age from 17 to 85, with an average, or mean, age of 45 years; their annual family income ranged from less than \$20,000 to more than \$50,000. Participants make their homes in diverse communities within several regions of Nova Scotia. In particular, the geographic categories represented in this sample include rural communities (33), villages (4), towns (33), and cities (31), as well as other geographic categories (6). Participants also represented a variety of ethno-cultural groups, including First Nation peoples (on and off reserve) (15), African Canadians (16), Caucasians (49), new Canadians (13) and Others (14). Twenty-three (23) of the participants also identified as individuals with a disability. (See Appendix D for demographic data.)

The average number of years which participants had spent caregiving was 10, with a maximum of 71 years. Non-caregiving work activities reported by participants reflect the reality of many caregivers, with several participants involved in paid work inside and outside the home. With respect to paid work outside the home, participants reported full-time (29) as well as part-time (20) work. Six of the participants worked full time at home and six others worked part time at home. An additional 46 participants performed volunteer work outside the home, while seven attended full-time studies and nine attended part-time studies.

Participants had different reasons for becoming caregivers and had a wide variety of experiences which shaped their personal experiences with caregiving. These experiences have been identified within four main themes: professional roles, personal skills and qualities, gender and

race, and family dynamics.

Professional roles

Several participants identified that they had either a nursing background or experience as personal care workers (PCWs) which provided them with the necessary skills for caregiving. Although work-related experience could assist in preparing the person for the responsibilities associated with caregiving, they were not synonymous experiences. There was a difference between providing care for someone they knew personally as compared to having a more professional or volunteer relationship, as the following participant explained:

It seems as care providers the more attached you are to the person, the more you tend to devote or commit. You can't seem to walk away the same way as a volunteer or a professional care provider would be able to say, "This is my role" and then leave.

Having educational and/or work experience in the field of health care could be both positive and negative as it carried additional expectations and obligations on behalf of the care recipient and others. The enhanced emotional attachment associated with providing care for a family member or friend could result in a higher workload due to the increased sense of responsibility or obligation. This sense of responsibility could also be projected by care recipients, who "expect more from you" and increase the obligatory nature of providing care, something that one participant saw as a 'disadvantage'.

Another concern raised by the participants about having a health care background was that other family members without such experience were often not considered suitable caregivers. As a result, those with professional experience were required to be family caregivers while other

siblings were not, as the following participant explains:

I found myself in a caregiving role because I'm in the health care field and my mother would call me with different issues. You see things changing. With my brother, he can't see it, or he won't see it...or just doesn't have the ability to understand aging, health issues. You just know that something has to change, so I put myself in that certain role. They have to be cared for, taken to their appointments, if they get ill you have to make a move, and do the right thing. You have to care for them and make sure they're safe.

Personal skills and qualities

As well as citing that a professional background affected their identities and experiences as caregivers, participants outlined a number of personal qualities which influenced their entrance into caregiving. The link between caregiving and personality characteristics was summarized succinctly by an elder in one of the focus groups who stated, "Some people are caregivers and some people just are not". That is, caregivers tend to have qualities which facilitate their nurturing and providing care to others. Although many participants did not believe they were extraordinarily "caring" people, their perspectives were informed by their own personality traits and qualities.

Although one caregiver wisely pointed out that we never realize the skills as women that we do have, various skills and personal qualities, as well as several demographic factors, were identified as factors that helped them get past challenging situations and to continue providing care. These qualities were not just identified by the participants, but also served

to label them so that others perceived them as potential caregivers.

One participant reported that her desire to prove her personal strength helped her to provide care for her dying husband and to her brother with a developmental disability, despite the emotional and physical stress and challenges. She explained, "I didn't want anyone to think I was weak. I wanted people to think I was strong. I was a woman and I could deal with this, I could handle it. I don't need anyone else".


Recognizing that both the care recipient as well as the caregiver may experience a wide range of emotions resulting from caregiving was important for one participant. She valued her ability to accept and "forgive" the person for whom she was providing care for placing her in a caregiver role. The ability to forgive was cited as a helpful quality, as explained in the following dialogue with the focus group facilitator:

I think forgiveness comes into play for me.

Why do you say forgiveness?

Forgiveness to the person you're taking care of. Sometimes you can feel that you're put into this position. Resentful. Forgiving yourself for feeling that way, and forgiving the person that put you in that position. Because really it is not that person's fault that you're in that space at that time.

Thus, not only is valuing the ability to accept the care recipient and their actions, attitudes, and behaviours an important personal quality, but so too is valuing the role the caregiver is playing in the recipient's life. As one woman



explained, “Caring for your family. These are the important things in life. When you get old you’re going to say this was the best years of your life”. The impact she was having on her family became an important source of fulfillment.

The desire to reduce negative influences on the family underscored another participant’s provision of care. By providing care, she was able to ensure appropriate virtues and morals were instilled in her children:

And when I think of putting control into somebody else’s hands, that makes me very nervous. I have morals and values and that’s what I want my children to learn. I don’t want them to be with somebody who, is taking care of them maybe, but thinks differently than I do. As your kids get older, you hope that they’re always going to be thinking of what you think.

The concept of “control” was important for another participant as well. Being able to control how she reacted in stressful and challenging situations was an important quality she possessed as a caregiver:

The only thing I have control over is my attitude, my perceptions. You definitely need to have a good attitude because it’s so multi-task. If you don’t have a hold of that aspect of things, you can [fail] real, real fast. So you have to be mindful of that. You have to have a lot of discipline and be organized. You gotta have flexibility cause when that organization goes out the window and

you have to have enough.

Large stores of energy and inner strength were also required for caregiving. As a caregiver for a person with a disability stated:

You get strength somewhere. When it’s put there you do it. How I did it the last four years, I’ll never know... grayer, but I did it. Earned every one of those gray hairs.

The ability to defy values held by society and promoted by the media was also a quality shown by a number of participants. In many cases they did this to protect the care recipient. One woman was concerned that the impression and values she was trying to instill in her children were contrary to images in the media:

If you’ve got your values and then the public/media have their opinion and it’s interfering with what you’re trying to teach your kids, they’re teaching the opposite of what you’re teaching them.

This participant defied the high value placed on paid employment that devalued unpaid caregiving:

It’s how society values [work]. It’s a problem in a way, because when people meet you, the first thing they say is “what do you do?” They want to know what job you have. But a lot of people don’t classify a stay-at-home Mom as working. It is. It’s 24 hour seven. They think it’s an easy job. It’s not an easy job. You have all the responsibilities, good days with the bad. We’re psychiatrists, we’re caterers, we’re chauffeurs. We

have all these different things, but yet we don't charge for this stuff.

Some participants saw the lack of value placed on unpaid caregiving as problematic because it did not allow for the reality of the situation to be recognized. Perhaps this was why the following woman's husband did not want her to receive professional support to assist with providing care for her mother-in-law:

My husband doesn't want me to have anyone in. I don't get a break at all. He doesn't want to look after his mother. He doesn't want to stay with her while I do anything, so I really don't get a break...He's going to be 75 in April. I'm going to be 70 in August. That's part of the reason he's resenting that we have to keep Gram. He thinks we're old enough now that we shouldn't be bothered. But I mean that's the price you have to pay if your parent gets old. It's not your parents' fault if they live to be old.

Gender and race

In addition to personal qualities and skills, participants identified that both their gender and their racial/ethnic identity made an impact on perceptions and expectations related to caring.

GENDER

Participants reported that women, especially women with a health care background, were more frequently identified as caregivers within their families and by their friends than were men. As the following women explained, caregiving is simply "part of being a woman":

I've been a caregiver for family

members for different times in my life. It's learning the boundaries. What I'm responsible for and part of being a woman, giving and caring. We take on that role, whether it's ours or not.

I think women just assume the responsibility. Years ago we weren't expecting to go to college or have a career. We were mostly at home and being mothers. Myself, I still have to shake my head to get that out...I take responsibility. I think women assume responsibility without even being asked. Women get the job done.

Participants also reported that male siblings and family members were less frequently called upon to provide care; rather, they were seen as only assisting if female members were not available. A woman living in a suburban area who provided assistance to her mother explained that, despite her brothers living in the same community as herself, they did little to assist:

I also have a mother who is 84, who lives in [a suburban area of Nova Scotia]. I'm one of 13 kids. She's pretty much in the same situation as my mother-in-law, where she has angina, and lives in a great big house that she brought us all up in and because I'm the single one of the family that doesn't have a partner, the burden always seems to get put on me. So, again, I'm the one who had to take vacation when she broke her ankle...a couple of the boys are still there and boys, like you

say, they don't get it!

RACE

Cultural background was identified by some of the participants. An African Canadian female caregiver and a First Nations woman living on reserve spoke of culture affecting their perception of what constituted caregiving. For both participants, caring was part of their lifestyles. As the African Canadian female caregiver explained, caring was simply a part of her “upbringing”:

Well, I was raised in a black community, and in a black community everyone took care of one another. I think it is ethnic to a point because in the black communities, not so much now as when I was growing up as a kid, if I went by somebody's home and I saw a senior doing something, if it looks like they were sick. . . I was taught that you went next door and helped them to do that. I think those programs are no longer there. I think a religious upbringing should have a part in everything we do. I think if we're truly Christians that the caregiving we are gonna give, whether we're in the black community, the white community, or whatever community. . . because if you're a true Christian, you're going to give anyway because that's part of what we're taught.

This caring lifestyle (as she explains) may not be so prevalent today, but it was a part of her cultural background. A female First Nations caregiver living on reserve, who had been brought up in a lifestyle of sharing and caring similar to that of the African Canadian woman,

agreed. Her cultural understanding of caring and openness extended not only to family and friends, but also to strangers:

There was a group of children going to the [name] program and the band developed this policy where they said if you're not a band member you cannot come to this program because we're paying for this service. That went totally against my culture because as a native person we feed everybody that comes to the door. You come in, you sit down, we feed you. You don't even have to ask. But that was broken and I just felt horrible, like I was culturally deprived or abused or something was taken away from me when that happened, because I had to turn these children away. You see what I mean? That went totally against my values and my upbringing.

Family Dynamics

The position that participants occupied in their immediate families carried with it a number of societal roles and responsibilities, which affected both the reasons they had become caregivers and their caregiving experience. Participants identified six different roles: single parent providing child care, partner of care recipient, adult child providing care for parents, parent providing care, grandparent caring for a child, and grandchild caring for a grandparent. Factors which influenced caregiving experiences for each of these family members included whether the caregiver and/or recipient had a disability and/or illness, support from outside friends/family, and the availability of financial and community resources.

For the single parents, both challenges and

advantages were reported. The main challenge was that as single parents, they were the primary or, in many cases, sole caregiver. Depending on availability of additional family members (e.g., parents, grandparents, siblings), the participants were restricted in their opportunities for removing themselves from the caregiving role. As one woman explained, “If you’re a single mother and you’re sick, you still have to get up and make sure your children are taken care of even if you’re half dead”. Another challenge identified by single parents was that they received attention primarily when their children were misbehaving. This participant’s children were stigmatized and discriminated against because she was a single parent and she received little support or credit for raising them:

I think in my role as a caregiver I realized I had a lot of work to do, with raising kids on my own and leaving, and moving from a small rural town... it’s like the only time as a single parent you ever get really noticed is if the kids do something wrong...I remember feeling very naive and wondering what the problem was, but recognizing that my kids were classified as [having a] single parent, and automatically that meant that there was something [wrong]. They were going to be prone to get into trouble. Sad part about that was my kids did fine, but there is no one there to say, “You did a good job”.

Caregivers who were partners of care recipients identified that the transition from partner to caregiver/care recipient created challenges. Moving from caring with to caring for the person was an adjustment. This transition was also a challenge for adult children who were providing care to a parent, as the following


participant explained:

I can tell you when I first came home, it took me a solid year or more to get readjusted. You lived by yourself for years and then you come home and you’re the child again and not that my mother made things difficult, but I felt that way.

A dilemma faced by children providing care for parents was the need to ensure the dignity of the parent. The following participant explained how she focused on facilitating such dignity:

I always try to put myself in their place, and think what would I feel like? And how would I feel if this was happening to me? So I find it hard to go there...I try really hard not to treat them [like children]. They’re not children, they’re adults.. and they’ve lived their life. But you would be surprised how many people treat them that way. They’re adults, they’re independent and they want the fullest life they possibly can. And that’s what I would want for myself.

Participants related that the level of support or assistance caregivers received from others (e.g., spouse, extended family, and friends) varied, with some reporting good support while others obtained very little. This participant concluded that balancing responsibilities related to her work (i.e., business ownership), caring for her children, and transporting them to activities was a challenge, but with her family’s assistance, her workload was reduced. She also described how her ex-husband had added to her workload,



rather than reduce it:

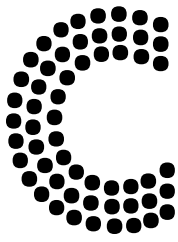
I'm a single mother of two kids and it is challenging. I have two girls - very rambunctious and getting them to where they have to go is definitely juggling the schedule and in trying to be somewhere yourself. For instance this evening I have a daughter who had to be somewhere for six o'clock. My other daughter has a concert at 6:45 and the good part is I have family to help out so I got part of my family taking care of that but when I did live with my husband I had less help. I had totally no help when it came to... basically I had another child to juggle when I was living with my husband - trying to work around his schedule, the kids' schedule and then I was running a business as well and trying to keep peace and harmony and everything the way it should be going routinely in the home during the day.

In summary, the combination of a professional or educational health care background, personal qualities, gender and race, as well as position in the family, all played a role and affected the participants' experiences as caregivers. For some participants, all of these themes were relevant, while for others some were very significant.



Chapter 4: The Additional Work of Caregiving

“To me it’s a system of daily activities and since I do some home care, I guess I have to emphasize “assist” because it’s important for people to maintain as much independence and dignity as possible, so rather than doing for them, to assist them in their daily activities.”



Caregiving is much more than simply attending to the physical needs of a recipient. Caregivers have multiple roles and responsibilities, including advocating on behalf of themselves and the recipients, ensuring that recipients are treated with respect and dignity, and that as far as possible, recipients have input into decisions concerning their care. They also have to take care of themselves so they can continue providing care to others. All these roles and responsibilities have to be carefully balanced.

Balancing multiple roles and responsibilities

The challenge of balancing caregiving with the multiple roles and responsibilities related to paid and unpaid work meant that caregivers had little time for self and frequently experienced fatigue, stress, and other similar health concerns. As the following participant explained, sometimes she simply needed to vent her emotions in order to cope:

And my two always say “You never do anything with me”...and it’s, well, I don’t have time, between the laundry, cooking supper...going here, there, back here...So after a while I sat in the middle of the floor and went “Ahhhhh!...Ok... now I’m fine”. I do that a lot lately.

Advocacy

Advocating on behalf of both the care recipient and the caregiver was perceived as part of the work of caregivers by several participants. To them, the key focus was on ensuring that the public, paid caregivers, and friends were looking out for the best interests of the care recipient. Their main goals were to ensure that the individual was comfortable and was

provided with a high standard of care:

The third time the nurse came, she said, “you’re supposed to leave”, but I was more comfortable staying. I wasn’t comfortable with people coming in. They’re strangers in your home. You have to get comfortable but you also have to know when to say that they should leave. Especially if the patient is feeling uncomfortable.

Caregivers sometimes had to teach others about the care recipient’s cultural background in order to provide high standard care, as explained by the following African Canadian caregiver when describing how she has acted as an advocate for her husband:

But you teach them that. Because the girls that come to my husband didn’t know that. I had to say to them, this is the [correct] cream. It is important, but if we don’t have the black workers to do it, you have to show them. My husband has special products and they know now, that when they come in they grease his feet, they know that they are walking into a black home, you have to grease the person because our skin is dry. They know my aunt. She does Geri curl, we show them what to do. I just wrote a letter to the home care association telling them that they need to have sensitivity training for all of it. Our products, whatever, so that letter has gone out to their supervisor.

Another important component of advocacy is teaching others about the illness, disease, or disability. As the following participant

explained, this education was directed toward a wide audience, including family members, friends, and society:

You also have to do a lot of teaching, because people don't know. You have to make them aware of the illnesses that are going on within your families.

Teaching to?

To other family members and friends and family just as a community as a whole. I know in my husband's case you have to be always explaining when people ask, "what is MS?" What are the symptoms? What causes it? You have to always be out there. Even my grandchildren were out this week and they were asking different questions. It's important to be honest with people when they're asking, especially the younger kids when they don't understand. They deal with it quite well. When they first came to the house and saw their grandfather sick, they were like...Now they just come out like he's part of the family. Jump on the bed and do whatever.

In order to be a strong advocate, caregivers, like this participant, wanted to expand their own knowledge base:

Yes, you have to understand the mood swings of people who are sick. So you have to be able to understand, and you have to be able to read up on what's out there and what's new that can improve yourself as a caregiver as well as the

person that you're giving it to.

In addition to advocating for the care recipient, some of the caregivers with disabilities commented on the importance of advocating on their own behalf, saying that in order to be an effective caregiver, they first needed to change societal perceptions of people with disabilities:

We still have young women in their teens today and if they don't have role models, they don't have women to speak to, or they don't know what's happening and it's right here in Canada. In all disability groups. When I was in university, I didn't think I could be a mother. I was petrified. I hoped to get married. Because I was a little different. That would be nice, but am I going to follow suit with that? Am I going to be able to care for a husband? And have a child? It never came to thought. Having a disability, we are always trying to prove ourselves.


The following caregiver with a disability felt she needed to advocate on behalf of both women and people with disabilities:

... we are not sitting down and taking it. We are trying to get out there and fight and work and say to the government "Here we are".

Spouses and partners also reported a greater need to advocate on behalf of their significant other, especially if they had an illness or disability, in order to ensure optimal health care and treatment.

Respecting recipients' dignity

Part of the work of caregiving included ensuring



that choices about care were made with as much input as possible from the person to whom care was being provided:

To me it's a system of daily activities and since I do some home care, I guess I have to emphasize "assist" because it's important for people to maintain as much independence and dignity as possible, so rather than doing for them, to assist them in their daily activities.

Regardless of the additional time it took to encourage independence, the dignity of the care recipient was of prime importance:

Even the time it takes to get somebody out of bed and to get them dressed. I often think I'll be so surprised one morning. I'll go up and Gram will be dressed. And she never is. Time means nothing. She'll go in the other bedrooms and look around or play on her bureau or something. She'd never think of getting dressed. I don't like to take that from her, but when you're in the room for about an hour you think "let's do it and get down[stairs]". Yet you don't want her to think you're hurrying her or that you haven't got the time for her. But the least little jobs take a lot of time.

Working with the individual to ensure they had as much independence and involvement in decision-making related to their care also included palliative care. The following participant describes how she incorporated her care recipient's desires related to death and

dying:

But one thing I have promised him - - that I would not get him in an ambulance if he was still with it and could talk, 'cause he made me promise. "I want to die at home. I don't want to go to the hospital". Now maybe that's not right , but it's what he wishes.

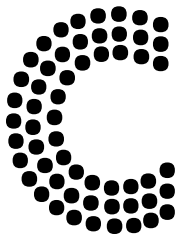
Abiding by the care recipient's wishes related to palliative care was also important to the following participant who was providing care for his partner who had HIV:

I had goals and objectives. I knew how it was going to end because I was the continuous caregiver. I got to go through all those stages so when he was dying I had already accepted he was dying, caring for him differently. I'm not fighting to save his life, and I became a much more gentle person and more nurturing because I wasn't fighting the whole system for what he needed _ I could focus on just caring for him, even though I was losing bits and pieces of him every day, as the dementia progressed and he then couldn't get out of bed any more. He still was my partner, he always was my supporter. He was the person I talked to, that I laughed with, that I expressed my fears to, and I continued doing that right up until 24 hours before he died.



Chapter 5: The Impacts of Caregiving

“In that moment, I have no idea. I didn’t believe it was having any effect on me, and I honestly didn’t know that a human being could be so focused. . . that [caregiving] was the only thing. Unless someone brought me a sandwich I wasn’t stopping to think ‘Oh, I’m hungry’. I don’t know if I even got hungry.”



caregiving had an impact on the health, work, leisure, and the need for adequate transportation and finances in both the caregivers' and the recipients' lives.

Health

Social, mental, physical, and nutritional health related concerns were identified by many of the caregivers.

SOCIAL HEALTH

Participants' social lives underwent severe changes due to the tremendous additional workload of providing care. Their social lives were affected as the inability to maintain social networks increased and friendships declined. As one participant said, "What social life?" Overall, the participants concluded that focusing on the care recipient and providing care for them meant that the needs of the caregiver took second place or even third or fourth place if additional caregiving was required. As one caregiver said, "[The care recipient] come[s] first. You're always trying to protect them, you almost never think of yourself."

One of the reasons for the decline in their social life was that time and energy was required to maintain friendships. One participant said, "I don't want to go out. I want to go to bed at night." Another said she found, "you can't keep the same friends very easily because if you went to lunch with them all the time [in the past], then that's gone."

Sometimes friends did not want to visit due to concerns about "bothering" the care recipient:

I think that your activities change because people don't want to come in, because they think they're going to

bother him.

As one caregiver for a person with a disability explained, "you've lost all your friends".

PSYCHOLOGICAL HEALTH

The caregivers also experienced a number of emotional, mental, or cognitive impacts on their health. Some of these were related to the stress associated with caring and its resultant physical impact upon the body. The majority of the participants experienced work overload in relation to their paid and unpaid work which resulted in stress. This overload often affected the ability to sleep, either resulting in insomnia or broken sleep patterns, as the following caregiver explained:

I'd say the sleep deprivation aspect. . . [the] debilitating effect it can have on anyone, especially if it's for a continuous period. My daughter is usually a very light sleeper and doesn't usually sleep more than five hours at a time, which is a hell of an improvement over the first two years of her life when she slept for three hours.

Another participant felt caregiving had negatively affected her memory and her ability to concentrate:

One thing I found when I was taking care of [my] husband was memory loss for me. I had so much on my mind that I would come to work...I can't remember...and think. You're talking to me, I'm hearing it, but it's not going

to the brain.

PHYSICAL HEALTH

Caregiving also affected the physical health of the participants. They frequently identified exhaustion and loss of stamina and strength related to provision of care. This resulted from both the actual tasks associated with caregiving, such as lifting, household labour, cleaning, and cooking, as well as its repeated and ongoing demands. One said she found herself, “refusing invitations to things as a result of being too tired,” and another said she experienced, “just complete exhaustion. Some days I just feel like giving up... just crying, letting the world just pass me by.”

In addition, caregiving sometimes resulted in physical injury to the caregiver due to the large amount of heavy lifting:

I got a hernia from lifting; she's been home last 7 weeks - she's a heavy woman, 180 lbs. Some days her legs are no good at all; she only got one leg if she has any, because the left side is gone. Heavy lifting all the time.

Some of the caregivers discussed such techniques as using towels to assist with lifting the care recipient. However, others reported it was not possible to completely remove the workload. Several participants suggested the need for either training or a “lifting service” that could be called upon as needed.

NUTRITION

Part of the health impacts caregivers experienced may have been influenced by their nutrition and diet. Many felt that they were eating poorly both in quality and quantity due to time constraints resulting from the multitude of caring responsibilities. As the following caregiver for

a person with a disability explained, proper nutrition was not a priority for her:

Sometimes when you finish taking care of everybody else, all you want to do is to lay down somewhere and food is way down there at number 23 or something, not a priority.

Many of the caregivers agreed that unless others mentioned or provided access to food, caregivers often did not have the time or energy to prepare appropriate or adequate food for themselves:

In that moment, I have no idea. I didn't believe it was having any effect on me, and I honestly didn't know that a human being could be so focused. . . that [caregiving] was the only thing. Unless someone brought me a sandwich I wasn't stopping to think “Oh, I'm hungry”. I don't know if I even got hungry.

Work and Leisure

Work and leisure were two commonly identified life spheres which participants found had direct impacts on their ability to provide care.

Work was only discussed by participants engaged in paid employment. Caregiving and unpaid labour responsibilities were not labeled as “work”. For many of the participants, paid employment was a financial necessity. They were required to balance their paid employment along with their caregiving roles and responsibilities in order to meet financial obligations. A number of challenges arose as a result of this balancing of multiple work responsibilities. One such concern was related to work schedule flexibility and being able to leave work if needed to attend to care



recipients:

It is additional stress when you're at work. If they need you, you can't get away, and sometimes you just can't get off either.

Try to set priorities, but you still have to be flexible because you never know when the school is going to call...and say they're sick and you have to come pick them up.

It's hard to plan...at work.

You don't plan, just live through it.

You get up in the morning, say "OK this is what I got to do", but will I get it done?

Another participant had to leave a paid position before retirement in order to assume a caregiving role:

I took early retirement. Guess it was meant to be. I had to retire to do what I'm doing! Now it's 24 hours, 7 days a week.

A few participants had given up their paid employment for caregiving, partly due to the cost, availability and inadequacy of the care available.

Giving up leisure to take up caregiving was quite common. Leisure was very important to the participants but constraints hampered their participation and enjoyment. Priorities were given to paid employment and unpaid caregiving. Caregiving meant, that at the least, leisure was often relegated to a lower

priority in the caregiver's life. In order to focus more attention, energy, and care on the care recipient, personal leisure was often reduced or removed from the caregivers' lives. The following participants highlighted the challenge of finding time for personal leisure:

There are practically no leisure activities. We're caregivers, we don't have time to do that. Unless you are a very organized caregiver and you have somebody coming in everyday.

I used to [have] a social life, a pretty good one. Out every weekend and now you might get me out once a week for a couple of hours. It's my time without my husband, just my time with my sister, spending that quality time with her...that we go to the show once a week, or once every two weeks. I came in to work last Friday and I said "Oh, I feel like going out tonight" "I think I'm going to go out" and it could be anywhere, then come the end of the day, I looked around and said "Oh no, I don't think I'm going to do anything. I think I'm just going to make cookies with the baby". As the day went on, I think, "Gee, I worked all week, and he was at the sitter and I don't I really need to go out". Then I stay home with him.

Caregiving tended to devour opportunities for leisure to the point that, "Leisure activities are gone". Participants added that even if caregivers were able to arrange time for personal leisure, they might face interpersonal constraints due

to a lack of partners.

Transportation

Transportation issues had a direct impact upon the caregiving experience and were affected by it. Although there were many additional financial concerns not specifically related to transportation, access to appropriate and adequate transportation was intricately linked with income and affordability. An immigrant caregiver outlined this relationship:

If you don't have money, you are not even mobile. You have to use the bus if you don't have the car. Using the bus you have to have a ticket or money. If you don't have money to get the bus, you can't get on. So money speaks all. Because if you have money, you can have your choice [of] what you want when you want [it].

The challenge of obtaining adequate and appropriate transportation was more frequently mentioned by immigrant caregivers, single parents, caregivers with disabilities, and caregivers providing care for persons with disabilities. Each of these groups more frequently identified concerns both with the current transportation system, their ability to effectively access it, and their lack of knowledge about how it operated.

Participants cited a number of areas where they had concerns about the transportation system in terms of the impact it had upon their daily lives and caregiving. Participants felt that there were insufficient options. In particular, public transit and the Access-A-Bus system did not provide enough options, times, or accessible vehicles. These concerns were most relevant for caregivers living in rural areas, where transportation was even more limited than in urban locales. It is important to note that 44%

of Nova Scotians live in rural areas, more than twice the national average of 20%. (Keefe and Side, 2003, p. 8)

In addition to the system itself, participants discussed their concerns about how best to access it. Some participants seemed to have more knowledge about how it operated than others. For example, the following two single parents had different understandings of what transportation costs were covered by social assistance:

Right now my car is dead and I was relying on that to get back and forth from work...\$10 a week for gas, and that's pretty cheap. Right now I'm spending \$10 a day for cab!

Social Services will pay for that. But you have to ask.

Another solution, identified by a caregiver below, was put forward as a suggestion to reduce some of the transportation *and financial issues*:

There should be a fleet of vans accessible for people with disabilities and they should be free. There should be a company that gets paid by the government, and they should go around like taxis are doing now, servicing the people who need to get to their appointments and such.

Finances

Beyond transportation-related financial concerns, a number of other expenses were identified by participants as having an impact on their caregiving. These costs included



alternative care provision, care recipient expenses (e.g., ambulance costs, special diets), clothing, housing, and extras (e.g., eating at McDonald's). Participants felt that when providing care, their costs seemed to quickly escalate and the basic daily living expenses were further compounded by additional costs if the care recipient required special care.

Two frequently identified daily living expenses which were a challenge for caregivers in this study were housing and alternative care. Finding affordable housing while on a limited income was problematic. The high cost of housing meant low-income caregivers had to pay most of their income toward it. The following dialogue between single parents captures this dilemma:

Drop the rates for the apartments . . . We have a friend who's looking, she's single, mother of one and he's not in school, and her [only] option right now is welfare. Welfare is going to give her \$800 a month and the [only] apartments she can find are running for \$450 -\$500 [each] before utilities.

I was in a one-bedroom for \$550 and I was on welfare. And the waiting list for the housing authority . . . you might as well hold your breath.

Another daily living expense was alternative care for the care recipient. Obtaining paid employment for caregivers with young children meant they had to arrange childcare. Yet, the cost of childcare was sometimes prohibitive:

If I decide to go to work right now, it would be a big decision because there is such a shortage of childcare, good quality, affordable childcare. The wages don't meet what you need to pay...So I

would say that's a big frustration over the years for me, available child care.

For caregivers with older care recipients, the same dilemma was identified. The cost of obtaining alternative care was often not affordable and, therefore, not an option:

I had no income. I have her bit of low income she gets . . . supports my household, I guess, and her care and my own. I have no other choice, nobody out there to watch her. I'm not going to put her in the home because she's not that bad...but it makes it hard where there's nobody else.

When we look at our own situations, I don't think we're in an economic situation where most of us can do that. Because we can't afford to pay someone to come in . . . It would be nice, but it is expensive. Even some of those insurance plans don't cover all that much.

Some participants reported a daily battle trying to cover basic as well as supplementary expenses. A single parent explained her struggle to pay daily expenses while her children wanted extras such as "Nike" running shoes:

Can't keep up [with] the Jones'. . . Can't get them Nike running shoes . . . The way I budget, I just don't have [it] . . . when I worked, I came home with money. I had money all the time...my kids were spoiled, but now even the money that comes from their father is so spoken for! \$75 cannot go to Nike

sneakers!

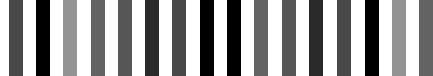
Participants also identified “extra” costs related to special care requirements of the care recipients, including necessities such as special diets, aids and devices, and additional medical care and drugs. The following caregiver for an adult child with a hearing impairment identified the additional cost for purchasing a hearing aid:

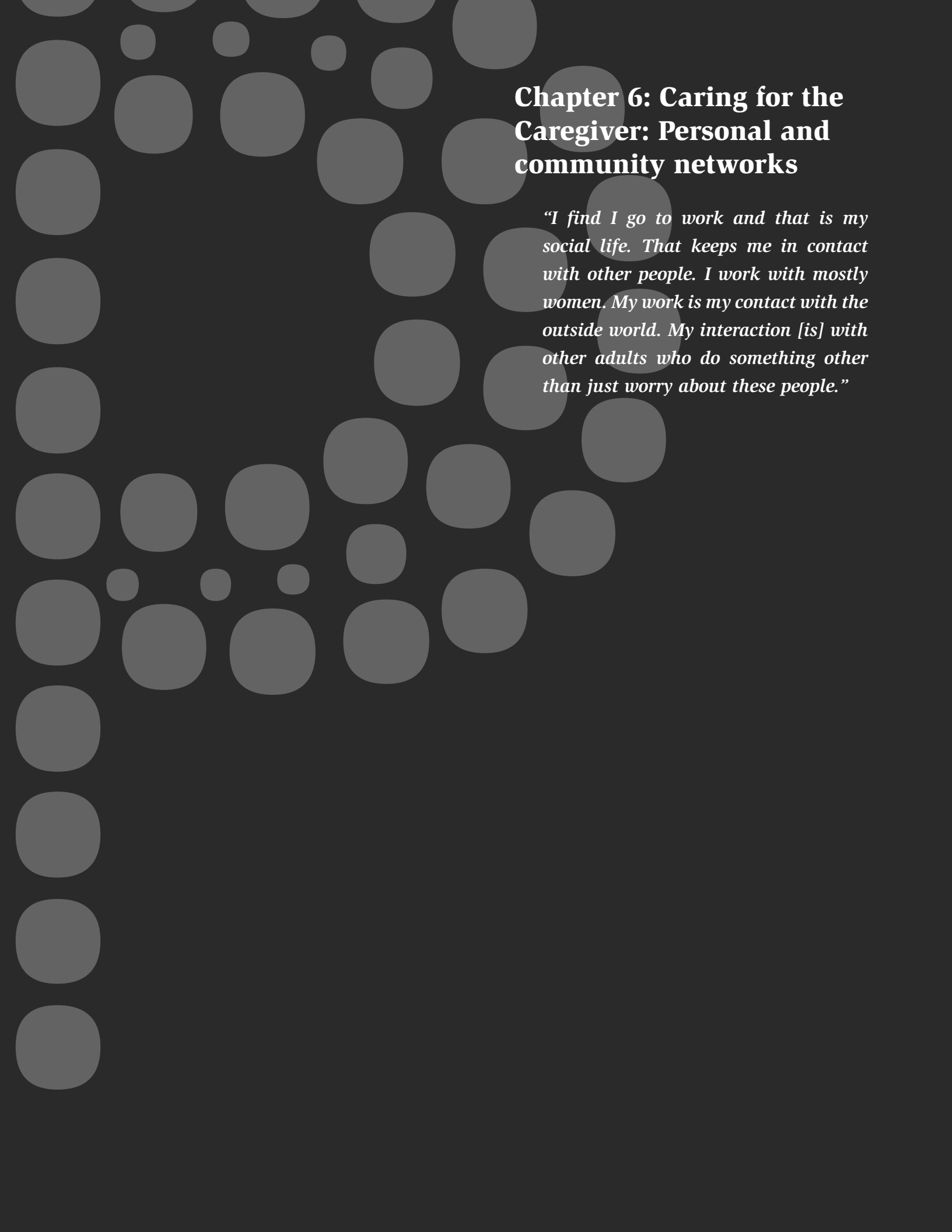
Even for my son . . . they will help children, but they don't help adults. It's over \$1000 for a hearing aid. Where am I going to get this money ?

Leisure activities were also constrained by cost:

If you have loads of money you can do all kinds of things because you don't you have to be creative about how you manage and connect.

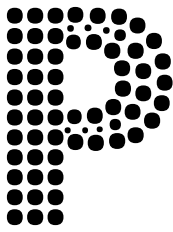
A small number of participants reported that they had access to money to cover costs, and that income was not a concern.





Chapter 6: Caring for the Caregiver: Personal and community networks

“I find I go to work and that is my social life. That keeps me in contact with other people. I work with mostly women. My work is my contact with the outside world. My interaction [is] with other adults who do something other than just worry about these people.”



Participants' answers to the question, "Who cares for the caregiver?" included self-care and the support of family, friends and the community.

Self-care

Caregivers identified a number of self-care and coping strategies, including having supportive relationships, and making time for humour, spirituality and leisure, that they used to facilitate their ability to provide care. These strategies allowed the caregiver to handle or reduce some of the challenges they might otherwise face in their day-to-day lives. Some were performed on their own behalf, while others were done more specifically for the care recipient.

Humour

Having the chance to laugh often helped caregivers, especially in challenging or emotional situations. Humour was used both to assist the caregivers in coping as well as to assist their care recipients in feeling better about themselves:

I also got relief in humour because I joked around a lot even when I knew he was dying, and I actually tried to explain to him that it's OK to go, that I'm going to be all right, I'm going to sort things out, don't worry about me.

Spirituality

Participants often turned to spirituality as a source of inner strength, especially in challenging situations. This support was provided both tangibly, in the form of spiritual support groups, as well as intangibly through their faith and beliefs, as this participant

explained:

I always look at the spiritual part and I think how would Jesus deal with this. Because we're spiritually involved, but we also have to keep going back. I think day to day, I do my spiritual readings and I also attend my church. My pastor is very good. We have a TLC group that is very powerful and for me, being connected to that group has been very helpful.

At the same time, some caregivers felt they developed a greater sense of spirituality as part of their experience:

You become more spiritual. You talk a lot. You hope for answers, ask for answers, looking for signs.

However, participants related that the challenge was in trying to create opportunities for their spirituality and its practice due to the time constraints caregivers experienced:

I am a practicing Buddhist. I've been in it now for 15 years. I have always had a rhythm. Morning and night. I've gotten so busy that I was making excuses as to why I wasn't taking time for me. I didn't have time. Clearly you could see it. But now I'm making that time again

While one source of renewal came through spirituality, other opportunities for enjoyment and self-care came with leisure activities.

Leisure

Caregivers identified a variety of leisure activities

that enabled them to enjoy a reprieve from their caregiving responsibilities. A wide range was described, from simply having a long bath, to reading a book or poetry or listening to music, to more physical activities such as shopping, gardening, taking a walk, and/or aerobics. In addition to specific activities, others described simply socializing with others as a form of leisure. For one participant, talking on the phone provided enjoyment and she described the phone as her “link to the outside world, especially when my kids were small.”

Walking was a form of leisure that relieved stress and invigorated this caregiver:

I just feel really responsible, always pushed, always in a hurry...I do take walks, I just have too. I need to get out, just for relief...I love them.

Finding time for leisure was often a challenge as caregiving could overwhelm their lives, but the participants recognized their need for leisure:

Because it's very easy to lose yourself in the caregiving. You wonder who you are. But more things you do that you enjoy for your own [self], helps.

One caregiver said that she sometimes put other commitments aside or postponed them until later in order to achieve this time for herself:

Isay, OK, dishes can wait till suppertime, I don't need to do them right now. And I take that time to paint or read.

Another constraint frequently identified was cost. The following participant explained how cost could restrict participation in leisure activities:


Another way I was lucky was that I

had money, so when it got to a point that I was thinking "I'm never going to get out of this bedroom again", I could afford to do something like phone a cable company and say bring me pay TV tomorrow, so there was another distraction for my husband, for me. We could have TV and 24-hour movies in the bedroom.

Leisure and finding ways of facilitating leisure, both for themselves and care recipients, was important to the caregivers. It served as a means of escape, enjoyment, and refreshment from the roles and responsibilities associated with caregiving. One caregiver believes that, “The understanding is growing and the realization that caregivers need to be cared for.”

Participants reported that, at times, caregiving could be a burden, and they occasionally needed both practical and personal support from others. The roles and responsibilities of caregiving often left caregivers feeling tense and fatigued. In particular, sleep deprivation, irregular meals and exhaustion all contributed to diminished physical and mental health, which translated into reduced capacity to provide care. Asking for support was not always easy. Caregivers said they felt guilty when they satisfied their own needs knowing that a family member had needs too. As one caregiver said, “I feel guilty looking for something for myself, thinking the kids probably need shoes. I deprive myself of something.” However, her friends recognized her need and would tell her, “You deserve this”.

Support-seeking was often motivated by the desire to indirectly meet the needs of the care recipient through an improvement of the health and well-being of the caregiver. Support brought with it additional resources and opportunities which then became available to both the



caregiver and the care recipient. Specifically, others provided the care recipient with resources that the primary caregiver could not, such as the opportunity for additional leisure activities. Supporters might possess physical abilities that the caregiver lacked, or interacted differently with the care recipient, thereby contributing to their improved mood and well-being, all of which was an indirect benefit to the caregiver.

Supportive Relationships and Behaviours

The stress of caregiving was seldom experienced in isolation. Individual caregivers and care recipients were often members of kinship networks that they relied on for support in their caregiver role:

I can go to my husband and say, you can go deal with him today because I'm not in the mood. I know it's OK to feel that way, because I'm human. That's called life.

Family members, such as parents, siblings, close relatives, and elder children, were often affected by the supports they provided. It seemed to have a “ripple” effect by enhancing health and well-being within the family. As one participant said, supportive relationships were, “not just building me. My whole family is built up by them”. In addition, participants said that supportive relationships provided children with opportunities for leisure activities and emotional support that were often beyond the caregiver’s exhausted capacity. According to some participants, inter-generation support, whether it involved elderly relatives caring for children, or children visiting with elderly care recipients, was especially beneficial:

My mother is 80 now, and I know if and when I get sick and I need assistance and care she'll be there, but I think I'd be reluctant because she doesn't need

that extra burden and strain in her life, the stress at her age. I would basically run her out of the house too, but in a protective way so as not to overwork her . . . She would be with [me and] my partner, 24 hours a day around the clock.

Trusted friends, neighbours, and teachers create the next level of support:

So when you have friends, you meet with friends. When you chat with some people, they make you feel better. They make your day.

Less intimate relationships with community organizations and institutions such as the church and the workplace, provided an additional buffer of support:

I find I go to work and that is my social life. That keeps me in contact with other people. I work with mostly women. My work is my contact with the outside world. My interaction [is] with other adults who do something other than just worry about these people.

One participant recognized and appreciated that she had both a supportive family and supportive work colleagues:

For myself, the resources that make it manageable for me to manage stress is my family. I have a good strong family support system. The other thing is that I go to work in a wonderful environment. If you have a good base at work . . . [where you can] talk if you are having a rough day. Somebody is

going to understand you. Resources at work make it manageable.

Support groups and supportive relationships were frequently identified by participants as a method of providing care for themselves and reducing their personal stress and fatigue in order to continue providing care to another. These relationships did not necessarily involve tangible assistance: “just being there” was often enough, as this participant explained:

I went to a support group when I was caring for my husband, when he was dying of cancer. Sometimes it was hard, though, because he used to be there [too] and it was hard for me. I also had good friends I trusted. I think that was a major factor for me. . . like the trust and friends just being there and family [and] the support group, knowing you weren't alone and going there to share with other people and seeing what they went through

Simply having a chance to talk with other people about issues unrelated to caregiving was a form of reprieve which allowed the caregivers to negotiate some of the challenges related to providing care. The supports they needed were both practical and emotional.

PRACTICAL SUPPORT

Practical supports generally involved responsibilities and pursuits which were unrelated to caregiving duties. For instance, caregivers identified the need to engage in paid work or to attend to household chores such as “mowing grass, carrying in the wood we burn.” They also needed help with childcare responsibilities, transportation, and having the time to pursue leisure activities or attend

religious or secular gatherings.

Some caregivers “traded care” with each other as a form of barter, which provided both with much-needed support, while minimizing the emotional costs associated with asking for help from family and friends:

Wednesday is my day off. I tell my friend, who is a single mother . . . I say “You make your appointments in the afternoon, I’ll make mine in the morning”, and she usually comes to my house, because I’m right in town, and she’ll go to her appointment and I’ll look after the three kids. That’s the way we work it out.

Others traded favours:

I have a car, and my brother always wants my car. So I say, “If you take my car, you have to do an hour of babysitting”. That’s the way we work things out.

Some participants received practical support from their churches:

I feel good about it, because my church came to me, asking me. We have a group. It’s called a Helping Hand Group. They came to me one day and asked, “What do you need done around the house?” I said, “Excuse me? What do I need done around the house? What do you mean?” They said, “Yard work, painting to be done, you need your fence repaired, you need your wood cut up.” I’m thinking, “OK I got lots



of stuff.” The women and men showed up. They cleaned my yard, they picked up wood, they put [out] anything that was supposed to go in the garbage bin. These are the women working just as hard as the men so it was real good.

EMOTIONAL SUPPORT

Many participants experienced stress, loneliness and depression:

Sometimes I’d feel resentful and I would think “Oh God, forgive me for feeling resentful”. Who’s taking care of me? Nobody. Every time I went out, it was never “Hi, how are you?” it was always “How’s [husband]?”

Caregivers claimed that emotional support in the form of empathy, appreciation and commiseration, was an essential element of supportive relationships. Caregivers described their need for non-caregivers to identify with some of the difficulties that caregivers were experiencing. They wanted others to understand the significance of the caregiver’s role, not only in the care recipient’s life, but also in the lives of those who would benefit indirectly through diminished caregiving responsibilities. Commiseration appeared to be a major component of reciprocal support among caregivers. Whether in the context of a formal support groups or individual relationships. The opportunity to share experiences of caregiving with other caregivers represented an element of emotional support:

My social life is a group of women that got together when we were all going through some kind of crisis at the same time. We all got together one day a week, my escape. The day of the

week didn’t matter, it changed because of my work schedule. So that’s my day out with the girls. We got together and we started to knit, learned how to knit. We’d talk about our feelings, talked about our husbands, the problems you had...and it was just like..it all came out.

When others validated their decision to provide care, and expressed approval about the manner in which that care is delivered, the roles and responsibilities of caregiving were perceived as less burdensome:

He’s a great worker, he’s good understander too. I guess I took on the role of looking after my parents and things so he was really understanding.

RELATIONSHIP DYNAMICS

The way that caregivers sought support and resources was affected by the relationship they had with family and friends. Historic family hierarchies, power imbalances, and past disagreements over the provision of care underscored the dynamics within which support was sought and received. Caregivers sometimes feared that the support they received would not be of the kind they wanted, and soliciting help often entailed submitting to intrusions that they did not consider appropriate. For some caregivers, adapting to different people and situations was often more difficult than not receiving support at all:

I look back now and think in a way I knew. If I just kind of let go and let Mom take care of it, I won’t be able to do this because then I will fall into that role of letting my mother be my caregiver and I couldn’t allow that.

There was also a certain amount of denial, and if I got to the point where I needed my mother to care for me or needed her to help care for my husband, then I wasn't doing what I was supposed to do and he really was going to die. I suspect that's probably a mother-daughter kind of dichotomy.

Although caregivers were somewhat reluctant to discuss this negative aspect of support, they did describe the way that people offering support sometimes imposed unwanted changes to well-established routines and gave unsolicited advice about the manner in which they should be providing care. This influenced the comfort with which caregivers received and subsequently sought support, but they felt that rejection of this unwanted “help” or advice was tantamount to “biting the hand that feeds them”; a position few weary caregivers were willing to assume:

We have worry and terror, we have stress, change of priorities, responsibility, sacrifice. We have change of role, we have resentment around people taking over, who does the work in the family?

Participants found psychological barriers were often more difficult to overcome than physical barriers because they are rooted in socio-cultural norms and values related to gender and caregiver identity. In particular, female caregivers were often reluctant to burden others, particularly their children, even if the support did not represent a significant imposition. Participants felt that in addition to being socialized to shoulder the burden of providing care, women are encouraged not to seek support and to assume that others (particularly men and children) lack the ability to provide the same quality of care. Social values such as stoicism also discouraged caregivers from

seeking or accepting support:

Well, you're not allowed to get sick when you're looking after somebody. Because nobody else is going to look after you. So you can't be sick.

I didn't want anyone to think I was weak. I wanted people to think I was strong. I was a woman and I could deal with this, I could handle it. I don't need anyone else.

These barriers were often rooted in individual expectations, emotions and identity. Some caregivers revealed that they denied their need for support because they felt resentful about the manner in which support was provided or the fact that they had to seek support rather than have it offered freely. Surrendering caregiving responsibilities, even temporarily, also placed caregivers in jeopardy of being criticized about the manner in which they provided care. Some caregivers revealed that this fear of criticism represented a major barrier to their seeking and accepting support.

For many participants, the role of caregiver was rooted in personal expectations of self-sacrifice and altruism. They often perceived these expectations to be standing in stark contrast to the solicitation of support in their caregiving responsibilities. Consequently, some caregivers felt guilty about desiring personal time, leisure or the attention of others:

I used to think that there was nobody in the house that could provide for him. [But] I found out when I went away for a week or so. When I got back he was looked after and things were done. Even some repairs were done. Now I know that they can take care of



business. That was a good lesson for me and I also came to the realization that not only can they [do it], but they want to [do it]. I don't think I gave them the opportunity, because I was so used to doing it myself.

For me it was really a humiliating moment when I called and I was crying. I was so lonely. For 4 months I was in the bedroom, and phoning and saying, "Please can someone just come and visit me, come and sit in my backyard for half an hour and have a cup of coffee with me?" I felt like I was begging, and I think I was pissed off too, thinking because I was so involved, these people were my friends as well.

people have a better understanding of that intimacy of dying and family life . . . This is family time -- they need to be doing what the family needs to do, and then when the person's dead, then we can come in. In the old days people used to get together for childbirth or the dying, but after the birth and after the death.

I found in rural areas people are more likely to bring over the meal and come and do the housekeeping and that kind of a community sense that you don't get in urban centres.

Culture influenced the manner in which support was provided, particularly in relation to palliative care:

I think probably in terms of the Aboriginal community, we've had so much premature death. It's only a generation ago that people started to die in hospitals, so there's a long history of a community knowing what to do and families knowing what to do.

Supportive Contexts

PROXIMITY AND CULTURE

Participants said that they were more likely to receive support without having to request it from people with whom they shared history or culture, or people who lived close by. Within these intimate networks, the needs of caregivers are often common knowledge. However, cultural differences related to family/community expectations about who should provide care sometimes limited the support options for caregivers.

Communal support, which involves the shared effort of many community members, seems to occur more often in small towns, rural areas and among marginalized ethno-cultural groups. However, some urban caregivers living in well-established neighbourhoods also reported receiving this type of communal support:

I also wondered at the time if rural

CAREGIVERS' EXPECTATIONS

The manner in which support was offered and accepted was discussed by participants. Many revealed that they often had to ask for help because it was seldom offered. This was a challenge for some caregivers as it required an adjustment in their self-concept so that they could ask for support with minimal guilt or shame. This adjustment often required more energy than many caregivers possessed. Nurturing, which was rooted in the caregiver identity, often extended to family and friends, whom the caregiver did not want to burden by

asking for support:

My brother comes over, but I end up cleaning and cooking and everything for him too!

It was for my dad before he died. Between all of us we did it, but I did a lot being the one who always has a car and borrow[s] money and does stuff. Being in close proximity, I will be the caretaker for kids and for parents which happens a lot.

I can call and say I'd like a couple of nights off, but there's never an offer. I'm waiting for an offer...that offer will never come. I will have to say..”will you stay Friday night? I haven't had a weekend for a while.”

THE REWARDS OF CAREGIVING

Despite the large number of challenges they faced, many participants talked about the rewards of caregiving. It was often the rewards that helped the caregiver negotiate the challenges:

Reward. The reward...that's the word I was looking for. You go through every bit of one of those emotions but sometimes there's a good day and it's not so bad ...and most times that you make it through that challenge it's rewarding because it's your goal. It's your challenge and you've made it and you provided child care or looked after a parent. Because it's certainly challenging whichever way . . . I think

a lot of that depends on who you are giving the care to.

Participants described one such reward as simply feeling good about themselves because caregiving enabled the caregivers to feel they had contributed something worthwhile despite facing challenging situations and, therefore, to experience a sense of satisfaction and enjoyment. As one participant said, “It is really hard but it is rewarding when you realize that you did all you could do.”

In spite of her concern about the potential length of time she was going to be a caregiver, this caregiver also noted her positive feelings resulting from caregiving:

You know, caregiving in one sense makes you feel good to know that you are able at that time finally to do something for them. But then in another sense the whole time you're thinking . . . you're thinking, “How long am I going to have to do this?”

Participants also felt that providing care brought a sense of accomplishment. Particularly for the caregivers of children, recognizing the influence they had on their children and the knowledge and skills they were able to instill provided a sense of achievement:

So when they turn out the way that you taught them, it makes you feel like “well, I did a good job” and give myself a pat on the back. It makes you feel that they're going to be okay. When they go on their own, you know they're not going to starve, they know how to cook for themselves. They know how to



clean clothes.

The other predominant reward associated with caring was the education the caregiver obtained. This education was in two areas: learning about the health care system and caregiving, and learning about their own emotions.

Learning how to access resources within the health care system, as well as many of the nursing skills associated with providing care, were obtained through daily practice. One caregiver explained how she obtained such skills:

One of the things that is good about being a caregiver is that you learn an awful lot about caregiving. You learn about how it works. You learn an awful lot what it entails so that you can help others who are caregivers. You're not boasting or anything but I have given suggestions . . . [about] where to go in search of what they needed, how to go about getting a hospital bed. There are ways of doing it.

Most of the learning described by caregivers was in relation to their emotional and spiritual growth. Participants described a number of traits such as compassion, patience, and understanding that they had developed through their work as caregivers. They also described their spiritual growth as a better understanding of their role, as the following caregiver explained:

You grow from it...you get more spiritual...higher faith. You know you're not alone. I don't think I'm a religious freak but I believe we are always at a time in our life where we're supposed to be. I think we are there for

a reason.

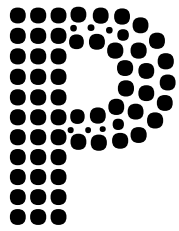
One participant tied together emotional and spiritual growth when describing the learning process he had gone through as a caregiver:

It teaches you patience, self-confidence and self-assurance. There's no other way you could get it. Those are such little words for what it is I'm trying to describe. I think probably it has more to do with spirituality, the spiritual side of self-confidence and self-assurance.

Chapter 7: Organizational Resources

“Sometimes when you use resources, like the bus you were talking about, you single your kids out. So having the bus which allows your daughter to go to school and be safe means you don’t have to walk her to school, but then she’s the girl on the bus, so socially it impacts.”

Supportive Networks



Participants described physicians, home care workers, Victorian Order of Nurses (VON) workers, hospital staff, support groups, church/spiritual groups and employers as members of a more formal support network with whom they had regular or intimate contact and/or a more intimate physical or inter-personal relationship. Other health professionals, workshops, and various community organizations with whom caregivers had less direct or prolonged contact and/or who provide less personalized support were also named as supports:

There are some positive things and some challenges. We talked a bit about pediatricians, occupational and physiotherapists.

I find the Health Department is a good place to go to look up information and to help you with things.

I feel happy when I go to the YMCA because it's opened for me many things . . . to go on trips, to have work, to be good in language.

I think there is more out there [now] than there was for caregivers because they have started support for caregivers through VON which is really good.

The resources available to caregivers, their families and the care recipient include those related to information, learning and capacity development, practical assistance, advocacy, medical assistance, and psychosocial support. They involve issues of control, coping and coordination, and creating opportunities for

leisure, learning and networking. It is important to bear in mind that caregivers often access “clusters” of resources from a particular source or at particular times, and these resources function together to “smooth out the rough spots” in the overall caregiving experience.

Individuals and groups within formal networks provided instrumental, emotional, informational and affirmational supports to caregivers. Many of these individuals and groups also acted as advocates for caregivers, through interaction with others within both formal and informal support networks. They contributed to care-related education, as well as group or one-on-one skills, and learning opportunities that facilitated self and recipient care. As one participant said, “They gave me skills. Yeah, and knowledge.” Another said, “They helped with his coordination, a lot of exercises and they taught me how to be creative with him and try to help him focus on certain tasks.”

Physicians and allied health professionals often coordinated medical/health care. Some employers permitted flexibility in work schedules, and this eased some of the stress involved with merging paid work and caregiving responsibilities. Various community organizations and church groups offered affordable childcare, or provided financial and/or material resources that permitted caregivers to access additional supports. Some community organizations also provide recreation and leisure opportunities at little or no cost to caregivers.

Participants also reported that individuals and groups within formal networks provided emotional support by easing caregiver stress:

Crisis counselors - they help me a lot relieving my stress, working with me and my family, trying to solve the financial problems and all the domestic [ones about] how to manage

everything.

They also provided a “space” where caregivers could interact with others outside the caregiving environment.

Support Contexts

Formal supports provided a relatively objective context within which caregivers could express their concerns and problems without fear of creating tension that might lead to interpersonal conflict:

I have actually paid psychiatrists and psychologists to go sit down and talk about the stress I'm feeling or the overwhelming stress of it all and have paid my set fee, whether it be \$150-\$80. And sat there and cried the whole time, but left there feeling ever so good. I was ready to sing. I felt good. I just wanted a safe haven to cry that out.

Yes . . . I advocated for it because I feel sometimes you can't talk within the family about certain issues, all issues that you're dealing with. But sometimes you just don't want to have to say it, or justify it or explain it or get any feed back. Just want to let it go, go home.

However, participants pointed out that individuals outside the caregivers' informal network may not fully appreciate the subjective impact of caregiving, and formal support was often limited to supports related directly to addressing care recipient needs:

I think sometimes [it's better] if you're telling [about] your situation

to somebody that's either been there or can really relate. The social worker told my mother to take [care recipient] home. She cannot take [care recipient] home, because she's physically and mentally stressed to her limit.

Information Resources


Caregivers cited information resources as a major source of formal support. In particular, print material and the internet provided useful information about specific conditions that affected care recipients. Informational resources enhanced caregivers' abilities to cope with the uncertainty they experienced around caring for someone who was very ill. Information also improved the caregivers' capacity to provide care and expand the knowledge of those within the caregiver's support network:

It helps. You don't get as frustrated when you have an understanding of. . . this is a symptom of. . . this is how this person should react. . . makes you feel better about what it is you're doing. That's continuing education.

So it's been good for that, for new information that's out there, we're getting a lot through here. However, participants noted that information resources may not be accessible to all caregivers. Similarly, they cautioned that information must be prepared in such a way that it is comprehensible at many levels of literacy.

Capacity Development

These resources were identified as mainly



originating with community organizations. Community and family resource centres provided a wide range of programs related to family and general life skills. In addition to community kitchen classes about healthy meal preparation and storage, caregivers accessed programs related to first aid training and adult care.

Among caregivers who are newcomers to Canada, organizations such as the Metro Immigrant Settlement Association (MISA) provided critical human resources as well as capacity building and literacy programs.

So MISA put me with the right people. MISA really helped me a lot. They put me in the program to know what are the Canadian rights here in Canada.

Practical Resources

These assisted caregivers with a variety of tasks, some not directly related to caregiving responsibilities, and included childcare, transportation, daycare for special-needs children, and meal delivery programs for elderly and other caregivers. Some participants cited financial support, accessible through social assistance programs, as another practical resource. Home care was cited as one valuable practical resource:

Home care is really wonderful. It's not enough [sometimes], depending on the situation. With my Mom, it wasn't long enough but it was wonderful to have that.

For people who are home, support workers are wonderful. I just couldn't do without them. They come in every morning to give his bath; in the afternoon they come back and freshen

him up, but it's a social thing too, for him as well.

The home care. I have eight hours for one day a week. She's very good and Mom really loves her.

Other participants talked about community kitchen programs which permitted caregivers to collectively prepare meals in advance. This combined opportunities for social interaction with practical, time saving support. The Access-A-Bus service was named as a practical support that was extremely useful, but did have its drawbacks:

Sometimes when you use resources, like the bus you were talking about, you single your kids out. So having the bus which allows your daughter to go to school and be safe means you don't have to walk her to school, but then she's the girl on the bus, so socially it impacts.

Community churches were identified as a source of respite, personal and house care. However, many participants indicated that formal, in-home care is the most critical source of practical support, including caregiver respite, personal care, and house keeping services. This resource was especially important to disabled and elderly caregivers who required additional assistance with the physical aspects of care:

I had to go to a funeral and I didn't know about the funeral until the night before, but she wasn't working in the morning, so she came. She's my "quick change" if I need [help]. . .and if she's not working that shift. So I'm lucky

that way. A good feature.

Watch TV. Read. Go to card games once and a while. I know there's somebody to stay with mom for a couple of hours. I can get Home Care to come in sometimes. How long? 8 hours every Friday.

I have Home Care; I have a nurse comes in twice a week on Tuesday and Saturday mornings; and all the other mornings I have the home support agency girl come in. And then I have a visit from...in the afternoon. Just wonderful and I couldn't do without it.

As a person who has a child born into that environment [I have] the opportunity to have government dollars to pay for respite staff. I don't think my marriage would survive, I don't think my children would be very functional, my son in particular. Because of the freedom that allows us to live a "normal" life.

According to participants, the Red Cross provided practical resources for care recipients in the form of equipment such as walkers, wheelchairs, commodes, chairs and beds. Other devices which appeared to be of particular significance were those that facilitate communication and connection between care recipients and caregivers, including bells, cell phones and horns. In addition to relieving some of the physical burdens of care, equipment improved the quality of life for care recipients

as well as protecting caregivers from injury:

I know when I did hospice nursing they had a telephone system and they also had the push button. You could wear the device and it automatically fed into a computer.

I have a room in one end of my house and I can't hear him if he needs something, so I have a bell. He doesn't abuse it; he uses it when he needs or wants a cup of coffee and I told him, "If I hear the bell I'm not going to get upset and think you're in dire needs" because he can't get up on his own, or get a cup of coffee, or close the window, or anything; and the phone is right beside him, so he can answer that, and so I have a bit more freedom than I did.

Advocacy Resources

Legal aid was recognized as playing an advocacy role for caregivers:

Legal Aid, when you really can't afford a real lawyer. When you don't have the finances to hire a lawyer, the Legal Aid makes you feel you still get the job done.

Family physicians and allied health professions were also mentioned:

The doctors are totally backing me up. The physiotherapist said the other day, "I can work with other kids for six months to get him to do what he's



done in two weeks”.

Medical Resources

Physicians and other health professionals, such as public health nurses and hospice care program workers, provided medical resources which directly supported caregivers and their families. These were acknowledged as important resources for caregivers. In addition to assisting caregivers with coordination of care and promoting health care skills, medical resources provided a critical link to current research about illnesses that affected care recipients:

You get that together...the forms and everything filled out, and the doctors doing whatever they're supposed to do and give those back to where they're supposed to be and that's how we dealt with that. It's a lot of gathering of information and then to get that processed is another little wait. Everybody's been co-operative.

They are doing research now and the doctor I see, he's the head of that, so he's really, really good. He's the best there is. They were excited to hear that we were going up there. We weren't so excited, but they were...because that's what they do.

Psychosocial Resources

These “clustered” resources, which emerged as a critical source of support for caregivers, were often provided through community services such as “Seniors for Seniors”, which is a telephone support service available to elderly

caregivers:

I know there's a Seniors-for-Seniors or something like that, that calls seniors on a regular basis to see that they're well, OK, or bored, whatever, just to create some conversation, get them on the line to make sure they're well.

These community resources, which provided practical assistance to the caregivers, also served social needs and helped build caregiver networks. These supportive networks often emerged from a collective need to develop strategies for navigating the “caregiver system”. Opportunities for recreation and leisure, provided by respite care, were especially important for maintaining family cohesion, and allowing families to lead something that resembled a normal life. Mental health counselling services for caregivers and their families were also a highly valued resource.

The county does have some programs like recreation and leisure because they're into accessibility for everyone. The day camps . . . sometimes they hire special coordinators who are equipped.

Social Implications of Accessing Resources

PERSONAL CONTEXTS

Personal contexts refer to coping or adjustment on the part of the caregiver in order to access resources. Ironically, in-home and respite care represented a source of stress for caregivers because it involved giving up control and trusting a stranger to care for a loved one. Moreover, caregivers often had little control over when care was provided, and this limited the benefit of in-home support. Participants reported that in-home care can be intrusive, and that it is

especially important for home care workers and caregivers to work closely in coordinating the care so that it is not disruptive to the care recipient, the caregiver, or to informal support networks:

Anyway, my biggest thing is trying to deal with the guilt of not spending more time with her; if I have time to take her shopping, I do, but if not, she gets Senior Wheels, but I encourage that...and I think my biggest problem is she has to understand the guilt of not being there as much as she wants me.

You know what I found with the home care? It was stress, edgy. You were going, you were tired, but you had to do your thing. You didn't get relaxation and your rest was not restful.

One of the most distressing findings relates to confidentiality in the context of caregiver resources. Some participants reported that the stigma attached to certain diseases such as AIDS encouraged them to conceal the origin of the care recipient's illness in order to ensure that resources remained accessible. Maintaining this pretence became yet another stressor for caregivers, who needed to also ensure that care recipients and members of the informal support network did not disclose the true nature of the illness:

In my case, there was a hospice starting in our area and a couple of people did come over and sit with my partner, but I had to lie about it. He had a "brain tumour". There is so much lying and

deception in caregiving.


Would you have had as much problems if you had cancer, or is it a rural health care problem with HIV being another layer?

RELATIONAL CONTEXT

Participants acknowledged the importance of maintaining good relationships with those who are in positions of power in order to access the resources they required. Caregivers often walked an interpersonal tightrope of diplomacy held together with a healthy measure of humility in order to secure resources for themselves, their families and/or their care recipient. For example, some participants reported having to tread carefully with primary support resources such as physicians, who might actively dissuade caregivers from accessing alternative resources.

Meals on Wheels showed up at our house once, and the food was so awful. I don't know what they think people who are chronically ill or dying notice, but it's all pinkish-grey mush that smells -actually they came twice. The volunteers were very rude. First of all they were stunned that a woman in her mid-30s would be opening the door to Meals on Wheels, and they all felt it was well within their rights to ask why was I getting Meals on Wheels. The food was just not edible. That was the thing that surprised me the most, and again going back to that whole age thing, I was too young to be going through this.

In-home care typically involved some personal



or social interaction between a home care worker and the care recipient. These interactions were influenced by individual personalities and temperaments as well as the quality and consistency of care. The success of in-home care often hinged on the caregiver's ability to negotiate with the care recipient around what forms of outside care they would accept, as well as what manner of care the care worker was prepared to provide. According to participants, external care workers do not always understand caregiver needs, and tend to focus narrowly on the care recipient, with little consideration of the extent to which their work might influence the caregiver's life:

That means a lot. If they don't like the caregiver, they don't want them in... and it gives you lots of problems.

The Home Care is good; if you can depend on them. If they say they're going to come in at 9:00 o'clock, then they come in at 9:00, not 12:30 or 2:30 to give somebody a bath.

SOCIAL CONTEXTS

Caregivers living in small or rural communities had to consider issues of privacy and confidentiality when members of the immediate community provided in-home care. In addition to their immediate responsibilities for providing care, caregivers also had to adopt administrative roles that were sometimes hindered by resource bureaucracies. While these activities did not always tax financial resources, they required the caregiver's time, something most found in very short supply. The added stress of these organizational and managerial responsibilities reduced some caregivers' capacity to effectively access resources. In fact, participants reported that the necessity for extensive planning and rigid compliance with resource-related procedures effectively prevented them from

accessing certain supports.

The insufficiency in formal supports meant that caregivers relied on family and friends to achieve the full measure of necessary care. For caregivers with limited support networks, this meant struggling to perform double duties, filling in the holes left by burdensome bureaucracies and inadequate resources.

You have to do it. Like I say, we got a visit from the DVA [Department of Veteran Affairs] yesterday, and [the worker] said "Why don't you have a cell phone?" I said "I have a sitter for him when I leave and when I leave, I want to be on my own -- I want no tails" -- because I don't think that's very good for your health.

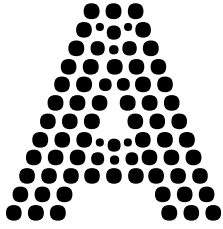
Many years ago in NS there just wasn't any. When he was actively dying, what I was allowed in terms of home care was three hours a week of nail and hair care, and I was thinking his nails don't grow that much a week that they need to be cut. So I think I was getting an hour and a half, two days a week. At one point he needed an IV started and [I called] the VON nurse and [heard] her say, "Because you live in Dartmouth it's against the law for me to do that. If you lived in Halifax I could start the IV. So you're going to have to learn how to do that at 3:30 on a Saturday afternoon". Looking back, seven years ago there just wasn't anything available, especially for HIV, especially in a rural area, but for any terminal disease. There wasn't a lot available.



Chapter 8: Barriers and Gaps in Support

“I was caring for two individuals who weren’t related, and I became very close to them and when they passed away, I had a very hard time with their deaths. As caregivers, I find talking with women from my own community that have dealt with people dying [helps] but I find that with caregivers there’s no respect, no support for caregivers. They’re just clients.”

Support Barriers



lack of awareness about what programs and services were available presented a barrier to accessing services. This lack was compounded by the isolation many caregivers experienced due in part to financial, social and economic circumstances. Financial barriers were especially relevant for caregivers who required in-home and/or respite care. Although paid care provided a measure of control, inadequate financial resources undermined caregivers' control over what resources were available and also affected the degree to which caregivers controlled when and how those resources were provided:

I did, but like ____ sa id, I've left her at the home, but it's very expensive; you really can't really afford it. Lately I don't think restive [sic] care is available.

Geographic barriers often compounded financial barriers, particularly when resources were not evenly distributed across regions:

One thing I will say I need is Access-A-Bus. I've contacted them. Access-A-Bus does not come to [rural area]. I have to pay for a private cab. If I want to have my husband taken [somewhere].

I think that [resources] has to do with the area you live in.

The word Access is a misnomer.

In addition to disparities in the provision of services in urban and rural areas, participants reported a lack of consistency in both the delivery and quality of home care. Process-

related barriers included inequitable eligibility criteria, which placed restrictions on in-home care, and created substantial difficulties for caregivers with limited personal resources. Some participants also described a punitive and suspicious application process for government funded in-home support, in which caregivers were made to feel guilty about requesting help. Similarly, time lags created difficulties in the processing of applications for resources, which translate into extended waits for in-home care. Ultimately, financial barriers emerged once again to create a two-tiered system consisting of those who can afford to hire private, in-home support and those who must depend on government or community resources:

People are giving them money, giving them food and thinking..."oh, we're making sure people eat". Who's going to go there and give them a hard time? Are you not going to have enough food for kids in the house?

If we're at a point where there's somebody at your house . . . understand that people coming into your house is a huge invasion of your privacy. There are days or times when we say "Sorry, but get out of here, we need some time". I would not consider myself in full control, but I would certainly consider myself in moderate to high control because of the luxury of having dollars to pay people to help.

PHYSICAL BARRIERS

For most caregivers, the pool of potential supportive relationships was small and was further constrained by a number of factors. For instance, in cases where respite care was required, participants believed that few

individuals possessed the experience, physical strength, skills, and/or coping style to adequately provide care. Even when caregivers felt comfortable with an individual's abilities, this other's involvement sometimes created tension or disagreement within the supportive network. Finally, respite care or other forms of support involved adaptation to others' schedules which negatively affected the caregiver and/or the care recipient. Caregivers were often reluctant to seek support from those individuals whose schedule left them little time. Although few caregivers refused support when it was offered, most acknowledged that the degree to which they benefited from that support was also constrained by time, resources, and geography. This became so burdensome to negotiate that caregivers often did not seek support:

I have a lot of friends here, but of course people are working and sometimes you don't want to bother other people. Sometimes you are not sure if you have the right [or] the choice to ask for certain things. You have no choice. But because it's a short time, you are not sure what kind of support you can expect from other people.

Palliative care, care for caregivers. My family are all away so that makes a big difference too. I was the primary caregiver and that was basically it. I think we need to learn to ask [for help] and one of the things they told us at Care for Caregivers [is] you need to be specific: Can you come Thursday night from 7 till 9? We need to do more of that as caregivers and "will you bring supper Friday night because I'm going

for the weekend".

A lot of times the caregiver becomes the care needer and there isn't the support in place. That's why I can't stress enough, especially for women living in rural Nova Scotia who are caring for others . . .and that's not limited to just people who require care on a health level, it's for our families and everything. . .Take care of you first, because ultimately it's only going to be you being responsible for you. [Remember] so you can't run on empty. You can only do it for so long.


Gaps in Support

Participants described a variety of general circumstances and specific instances when support was either absent or inaccessible.

Logistical circumstances such as geography, or the interpersonal relations and social expectations around supports, often presented problems for the participants:

There was a balance there. I sort of had an expectation that they would watch over me and say, "You can't stay awake for 23 hours a day for 4 days in a row, you need some help". But they didn't do that.

Gaps in practical support took the form of diminished physical assistance, lack of assistance with childcare, home care and transportation. In particular, lack of transportation was identified as a deficiency in formal supports available to caregivers, particularly around transporting care recipients to and from various health care appointments. Lack of personal resources was



cited as having a significant impact on not only the quality of care participants were able to provide, but also on the availability and accessibility of formal and informal supports. A related issue emerged concerning the lack of employer-sponsored coverage to address the health implications of caregiving in the absence of adequate support:

I was caring for two individuals who weren't related, and I became very close to them and when they passed away, I had a very hard time with their deaths. As caregivers, I find talking with women from my own community that have dealt with people dying [helps] but I find that with caregivers there's no respect, no support for caregivers. They're just clients.

Psychosocial gaps in support converged around issues of awareness, acknowledgement and expectations. Many participants revealed that neither they, nor most members of their support networks, were aware of formal supports available to caregivers. Participants believed this was because of a lack of sufficient information and/or inadequate dissemination methods. In particular, participants suggested that health professionals need to stay “plugged in” to caregivers’ networks and provide information about additional avenues of formal support.

Lack of acknowledgement within both public and private spheres emerged as a substantial barrier to promoting the needs of caregivers:

When I hear “caregiving” what comes to mind is stress and also a magnitude of unknowns as well. Lonely people that nobody thinks about.

Not surprisingly, gender expectations emerged during women’s discussions of gaps in caregiver

support. The consequence of inequitable and unchallenged gender expectations is a lack of proportional support available to female caregivers. This gap exists within both formal and informal support networks and is rooted in beliefs about the relative value of male and female caregiving, and the extent to which caregiving falls within socially constructed gender roles.

There are many days when I would be more than happy to have someone take care of me for a change. That's the one thing we don't search for as woman. . . You do the best you can.

Participants succinctly and articulately answered the question of why gaps in caregiver support exist. Quite simply, unrealistic expectations and social apathy concerning the roles and responsibilities of caregiving translate into barriers to supportive networks, behaviours and benefits, which in turn translate into gaps in support. An example of the detrimental effect of social expectations emerged among some of the paid caregivers, many of whom attend to care recipient needs beyond those assigned in their duties. These caregivers revealed a general lack of support, typically based on the belief that individuals will not act outside their scope of practice for care recipients with whom they do not share kinship ties.

According to participants’ comments, there were disparities in access to caregiver resources. Caregivers’ personal life circumstances and resource delivery processes influenced their abilities to access or utilize formal supports.

I found one, she was wonderful. She came in good time...next day, I said “I’ll see you tomorrow morning”. “No”, she said. “I don’t know who’ll be here and I don’t know what time they’ll be

here”.

Reliable child care. It depends on where you live as well. That’s the other reality. Different regions have different [degrees]. For example, for whatever reason, the Annapolis Valley has many resources for special needs children, whereas the other areas don’t have any. A lot of those come out of the community rather than the government.

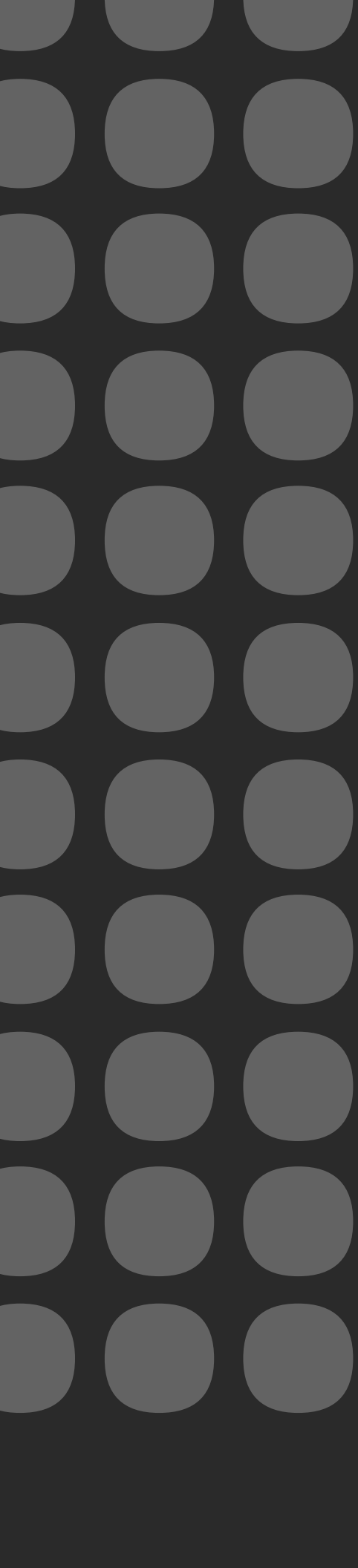
CONSEQUENCES OF GAPS IN SUPPORT

It comes as no surprise that lack of caregiver support translated into health consequences, which had a ripple effect on individuals, families and communities. From physical illness and injury to isolation, helplessness and depression, deficiencies in one area of support tend to leak out into other domains:

Well, I feel like giving up. I just feel like crawling in a hole and forgetting about the world. Then I get depressed, look in the fridge and [say], “Oh, food”!

My asthma flared up continuously. I knew I was at the point of having to go talk to somebody and basically air out my laundry, and kind of put my husband on the back burner and say “I’m focusing on you too much”. The breaking point for me was Mother’s Day. I felt guilty for being a mother. I didn’t feel like I deserved it, because I was putting him on the back burner too.





Chapter 9: Caregiving Experiences in the Equity Reference Group Communities (ERGs)

“Our caregiving seems to start really young with Aboriginal women, as First Nation women. I’ve heard people starting at 12 raising sisters and when they were done raising sisters, they started raising their kids and then after the kids, raising their grandchildren, so we’re looking at three generations of caregiving by the time we’re 40.”



●●● In this chapter we report the findings of focus groups with four specific groups: ●●● Aboriginal women, African Canadian ●●● women, immigrants, and women with ●●● disabilities. Although the previous ●●● chapters explored the shared experiences of all caregivers involved in this study, this section focuses on the specific, and often unique, experiences of the ERGs. Because the caregiving experience of ERGs are often poorly understood in the broader caregiving literature, this chapter allows for a further exploration of these experiences. Aboriginal women, African Canadian women, immigrants, and women with disabilities may have differential access to resources which results in challenges, such as not owning a vehicle or not having the resources to buy extra helpful equipment or respite care. They may also face challenges advocating on behalf of caregivers and recipients in attaining government health services as well, English may not be their first language.

Aboriginal Caregivers

Two focus groups discussions, conducted with Aboriginal women off reserve and on reserve, revealed three distinct themes which appeared to influence the experiences of caregivers from this ethno-cultural group: Aboriginal cultural traditions, as well as barriers and supports related to the socio-political contexts of Aboriginal women, and economic issues. Although some of these themes emerged among other groups of caregivers, they appeared to have particular relevance for Aboriginal women. Whether they lived on or off reserve culture influenced the caregiving experiences of Aboriginal women. In the case of the on reserve group, all of the women not only acted as unpaid caregivers but were also employed in “Adult Care”, a reserve-specific program funded by the federal government and administered by

local band councils.

CULTURE

Both on and off reserve Aboriginal caregivers emphasized the importance of culture in their perception and experience of caregiving. In particular, a combination of close relationships within communities, Aboriginal values, and an ethic of care, created an approach which was distinctive:

In our culture, it’s inherent. You look after your own folks, you look after kids, and whatever caregiving comes with that.

You’re obligated because they’re your family or your friends, and that culture, I think you still do it even though you don’t get paid for it.

As a Native person, we feed everybody that comes to the door. You come in, you sit down, we feed you. You don’t have to ask.

Participants explained that, within Aboriginal communities, extended kinship networks create unique caregiving arrangements which may involve many community and family members, spanning several generations. The special deference and respect afforded to elders was evidenced in the extensive and collaborative care participants received from a variety of family and community members:

Some of the cultural things . . .the grandmother raises the grandchildren and then down the road you look after her when she’s dying, so you could be

a caregiver very young.

*But they [elders] won't go to a home.
We take care of them right at home.*

*My grandfather . . . I took care of him
for three and a half years with no pay,
24 hours a day.*

*I started raising my sisters, then my
children, and then [looked after] my
aunt when she was sick and they had
no doctor then. Most of the time she
was at my house.*

Participants explained that, among Aboriginal women, caregiving is often experienced across the lifespan. Care is defined within the context of reciprocity, so that everyone from children to elders is viewed as both caregiver and care recipient:

*Our caregiving seems to start really
young with Aboriginal women, as
First Nation women. I've heard people
starting at 12 raising sisters and when
they were done raising sisters, they
started raising their kids and then after
the kids, raising their grandchildren,
so we're looking at three generations
of caregiving by the time we're 40.*

*With me doing that for her, she also
helped me too. I helped her in one way
and she helped me in another way. We
helped each other. I took care of her for
a while so she could get back on her
feet and then she was able to help me.
Basically, to me it's pretty much what*

caregiving really does.

The role of caregiver was intimately linked to the participants' identity and self-concept. Women in both Aboriginal discussion groups described caregiving as part of the traditional role of women within the family. One participant explained, "Some of us lost our mothers at a young age and we had to take over." On reserve women explained that kinship ties were reflected in caregiving activities and identity is linked to those for whom they care. Community relationships were often as closely linked by the participants as kinship ties:

*The more people who come in and show
you respect and kindness and all those
support things you need as a person the
more you feel good - "Gee, my mother
was such a very loved person in the
community, or respected."*

Participants had a holistic approach to health and healing. They saw physical, emotional, social and spiritual health as interconnected, and this influenced their caregiving:

*When they are coming into and leaving
the world, you have to be holistic.*


*It's important to capture those words,
"holistic" and "emotional care",
"spiritual care".*

*You [caregiver] are also a spiritual
support person too.*

*Not just the person directly receiving
the care, but the family.*

SUPPORT

The support available to on and off reserve



participants differed in some significant ways. Specifically, on reserve women emphasized the community as a major source of support for their caregiving responsibilities, and cited family members as playing a major role in respite care as their primary source of emotional support:

It's a cultural thing for sure. We have elders who come in and talk to you and they're giving you all these things . . . you get counselling, they tell you stories about a long time ago. They're kind of caregivers too, they're giving you the comfort and the emotional support you need.

When my mother was ill and my father, we kept them at home and took care of them, and just having different people come in [helped], they don't even say anything, they just come in and have tea, and you're sitting there saying, "Gee, I feel good I'm not alone, even though this person is not saying a damn thing, but they're here for me and I feel good about it."

Support also included the Adult Care Program, in which external caregiving was provided by people living in the community. However, this program of care often extended beyond paid caregiving roles, so that the "adult care" system appeared to blend paid caregiving with unpaid caregiving:

On the reserve, they get the Adult Care Program, which might not be much, but it's at least a respite for the relatives that are doing the non-paid caregiving. The Indians are way ahead of the Whites right now in home community

care, 'cause we've been doing it on our own on our little reserves.

With the exception of the Aboriginal Head Start Program, whose staff, according to one participant, "come out to your house when you're having problems", off reserve caregivers relied on formal community supports, which were not directed specifically toward the needs of Aboriginal women. For instance, one caregiver mentioned a parents support group which "doesn't cost you any money. They give you bus tickets to go home." These programs are typically administered through provincial or municipal community services.

Off reserve caregivers emphasized the need for cooperative programs, organized by and for Aboriginal women, as well as an off reserve liaison, who could facilitate support through their home communities.

BARRIERS

Many of the barriers perceived by Aboriginal caregivers related directly to their unique socio-political position. They believed that the restrictive and punitive system established through the Indian Act had far-reaching consequences for caregiving program design and resource allocation, as well as service availability and eligibility criteria:

The province . . .they're always saying the federal government will provide for you, and they're telling the band "You take care of your own".

Jurisdictional issues also created barriers when caregivers attempted to access respite care or additional support through the band, province or federal government:

I don't live on the reserve, so I'm not as Native as they are? I can see half my

family getting help, the government is paying for them, for people to build right on that reserve, but I don't want to live there. I should have that option.

I'd like to see the leaders in our community acknowledge and recognize that this work is valuable work . . . all our leaders are men, or most of them.

I just want to place value on home caring or caregiving and I want them to recognize that and say, "These women are valuable women and we need to give them as much support, either in terms of money, support, emotional or whatever, psychological, appreciation and thank you for doing this for our people and our community." We need to recognize that these are our people and our community.

Aboriginal women described the hospital system as often poorly responsive to the traditional healing practices of Aboriginal peoples, particularly for caregivers who attempted to provide healing that is of a spiritual nature. Cultural values of collective care, which might be reflected in hospital visitation by large numbers of people, were not always accommodated by hospital administration. This was also true for palliative care providers, who appear ignorant of diverse spiritual healing or caregiving traditions:

I think we drive a lot of people crazy when we have an elder or sick person in hospital 'cause there are so many of us. Most of the time, you're thinking, "This is not a circus, this is a person dying". But hey, we know that, but this

is the way we deal with it. That's why when working with different people, we ask for a private room.

Socio-economic disadvantage emerged as an important barrier to caregiving in both groups of Aboriginal women. In addition to providing necessities for the care recipients, adequate financial resources also permitted the caregivers to access avenues of self care related to leisure and recreation. The historic marginalization of Aboriginal peoples is evident in the lack of educational and employment opportunities available to Aboriginal caregivers, who experienced increased stress as a result of providing extended and extensive care in the absence of adequate resources:

We have a low education. The only job I can get is Adult Care and the nature of that work makes it so stressful for me to provide my own care at home.

Money does a lot. If you have a few bucks, you can get it done, and if you don't , it just causes stress for the rest of it. Lack of money is the problem. When we got it, we can survive but the lack of money can be stressful.

Recreation is also impacted by poverty or the environment. I wish we had a chance, our Natives, to have a chance to own their own house.

Traditional Aboriginal values related to caregiving created barriers to self-care for women in particular, who perceived these responsibilities to be closely linked to their identity, family obligation and social roles:

The person . . . if they can't care for themselves then they can't care for



anybody else. Some of us couldn't because we had other people to take care of. Someone said her life was on hold for a while, and a lot of us had situations like that. You just couldn't go out there and get your education.

For caregivers living off reserve, lack of culturally appropriate support was perceived as a significant barrier. Although interactions with non-Natives were not always negative, lack of Aboriginal home care workers and culturally specific caregiver supports off reserve limited their options.

I'd like to talk about adult care. Where we come from, on our reserve, whichever, you can almost choose who you want to be in your home, doing your home care. They come out here and you get your home care, but it's not by people that you would rather do it.

That would be easier for me, if I had group support because sometimes I would rather talk to a Native than talk to a non-Native, to get support and certain things.

It would be nice to have a Native professional there for childcare, someone that can relate to you more easily, which I believe would be another Native or adult care. That's what I'd like to see in the city.

I would like to see family support services, but for Natives. We don't have one that's for Natives. They have one

for the rest of the community though.

African Canadian Caregivers

Two focus group discussions conducted with African Canadian female caregivers revealed that cultural traditions, as well as specific barriers and supports related to the socio-economic contexts, particularly influenced the experiences of caregivers from this ethno-cultural group.

CULTURE

According to participants, caregiving begins in youth and extends into old age within most African Canadian communities. Consequently, the concept of caregiving is one of reciprocity and is not so much a distinct responsibility, as inherent in social relationships. Through teaching and modeling, this ethic of care becomes “normalized” across generations.

But the only thing new is the term. The concept, we've always had it.

We have all been associated with caregiving either as a receiver or the giver. We didn't become acquainted with it just in these senior years. We always were acquainted with caregiving.

We never put the two words together as one [caregiving].

African Canadian caregivers emphasized several cultural components of caring which were rooted in values related to reciprocity, stoicism and autonomy. Stoicism, while representing a psychosocial resource, also created additional barriers to their self-care:

I never thought about control. You

know what you have to do.

So nobody ever shopped for groceries for me because I didn't ask them to. You could also have health problems yourself. You have to set those aside.

SUPPORT

The social and geographic context within which many African Canadian women provide care created additional supports that benefited their caregiving experience. In particular, the African Nova Scotian community reflects strong kinship and community ties, typically through the “church community”.

According to these women, church members often acted as alternative caregivers, providing emotional and practical support as well as assistance to both caregivers and their families. Congregation members provided support through home-cooked meals, transportation, and respite care as well as emotional support through visitation and prayer.

The church is always there reaching out to you. At the service your name is mentioned and people remember.

Everybody was concerned and they were always coming to help. They would come and take care of this and take care of that. Somebody was always coming and going.

Extended kinship ties, particularly in small communities, created networks of individuals and groups who offered support to whomever was in need. One participant said, “As Black women in our community, where do we go? I guess we go to each other.” And another:

When you are a small community,

everybody knows everybody. What happens in your life, you don't even have to relay it; sometimes somebody already knows it. It makes the sharing aspect so much easier.

BARRIERS

Inadequate or culturally inappropriate caregiving support was perceived by many of the African Canadian caregivers as a barrier to accessing the help that they or their family members required. In particular, it appears that many professional caregivers do not receive adequate training related to the care of those from diverse racial backgrounds. In fact, personal care workers (PCWs) providing assistance to disabled African Nova Scotian care recipients appear to have minimal training around the needs of this population. For instance, one participant reported that a PCW used oil-based hair cream as body lotion on her family member because she did not know what the product was used for.

[When PCW workers come], you're supposed to leave but I was more comfortable staying. I wasn't comfortable with people coming in. They're strangers in your home. You have to get comfortable but you also have to know when to say that they should leave. Especially if the patient is being uncomfortable.

African Canadian participants expressed frustration with the need to “train” professional caregivers, as well as frustration with the lack of diversity within the professional caregiving community. Moreover, the cross-cultural education provided by these unpaid caregivers to professional caregivers had to be repeated several times due to a lack of consistency in the assignment of PCWs because individuals often

did not have the same worker twice.

African Canadian caregivers also cited socio-economic status as a barrier. This issue is particularly relevant for African Canadians, who tend to experience conditions of inter-generational poverty rooted in the historic racism of North American society. In addition to experiencing access barriers to external supports, low-income caregivers were not always able to accommodate the cost of essential resources. This lack of resources not only threatened the health of care recipients, but lack of respite care also proved detrimental to the health of caregivers.

When we look at our own situations, I don't think we're in an economic situation where most of us can afford to pay someone to come in.

You've got extra heating costs too, which is really expensive because that person is always cold so your heat is high, which is going to affect you financially and health wise yourself.

Finally, although small, closely-knit communities often provided additional supports for African Canadian caregivers, this intimacy also created barriers related to privacy and confidentiality when accessing resources within the community. One caregiver said, "They don't trust people all the time." Another caregiver explained:

There are a lot of referrals in this town that people could use and don't. [In] the black community [they might say], "I'm not telling them my problems. I'm not telling them my business so they

can go around and tell everyone".

Caring for elderly relatives also presented challenges in a culture which respects the dignity and autonomy of its elders:

Sometimes the word caregiving or caregiver to someone who is receiving it robs them of their independence. My mother was a very independent person and any attempt to rob her of her independence met with strong resistance.

Issues of personal privacy and inter-personal power were particularly problematic for African Canadian caregivers and their parents, as for this participant who said that her mother "wouldn't even get undressed in front of me."

Immigrant Caregivers

Two focus group discussions conducted with immigrant caregivers revealed four distinct themes which appeared to influence the experiences of caregivers from several immigrant cultural groups. These themes emerged from findings related to diverse traditions, many of which related to tensions between family care and self care, as well as specific barriers and supports related to the socio-economic contexts of immigrant women's lives. Although some of these themes emerged among other groups of caregivers, they appeared to have particular relevance for immigrant women.

CULTURE

All of the immigrant caregivers described diverse caregiving experiences within their own unique cultural context. Caregivers from several backgrounds revealed that the cultural expectations were such that women were required to accept the role of caregiver from a very young age. This was a tradition passed down from mothers to daughters and enforced

by cultural expectations. Consequently, many women in this group provided inter-generational care and often cared for a number of people over their lifetimes:

I spent a lot of time as a caregiver, with children and with adults.

I come from a family of six children and I am the eldest, so I've been a caregiver since I was ten.

The tradition for a woman . . . it is not really a law . . . that [if] you enjoy yourself people will think you are not a good mother or a good wife.

I have never heard of a woman as taking anything. She is always giving everything. With her husband, with her children, with her family.

Women also revealed that they were expected to care for their family members regardless of the impact it may have on their well-being. This practice reflects cultural norms that advocate caregiving as the “giving of self” and critical to the well-being of the family:

Love for the children. Respect for elders

If he is sick, I am sick too. If he is not doing very well, I feel the same. If he is doing well, I'll be happy. I know I'm playing the right role as a mother.

If my mother is having pain, I will feel

it.

In our culture we sacrifice all the time and give to our children.

Several women opted not to pursue external resources because they believed in the benefit of traditional practices. In fact, this group of caregivers expressed some concern about the tension between their traditions and those of the Canadian culture. Some women believed that in order to access adequate resources they must substitute their own cultural traditions for North American ones:

I have not adapted to the culture. I knew that it would be different. I am studying and I am working. I am taking care of the house.

Some of them [children] pick up from [Canadian] society and take it the wrong way. That really hurts the parents, especially when they are old.

FAMILY CARE VERSUS SELF CARE

In most of the communities represented in this study, family caregiving responsibilities superseded all others, particularly the need for self-care among women. Large, extended families which often span several generations translated into multiple caregiving responsibilities, leaving little time or energy for leisure or self-care. This is especially true for women who belong to cultures which reflect somewhat inequitable gender roles, where women must defer to their husbands about most decisions, including their own caregiving responsibilities.

When my husband comes home, he would be able to relax and rest. In my



culture, I have to obey my husband.

It seems especially difficult for immigrant women to balance the caregiving needs of family members with their personal need for relaxation and recreation:

At some point it becomes too much. It is hard to strike a balance. You need some time for yourself. It is hard for me to care for them full time.

Self-concept was often linked to family affiliation, and kinship networks represented a key source of identity and support. Participants' often made statements such as: "My mom is behind everything I do" or "My mom and dad always help me a lot" or, as one participant said, "In Africa, you go to a family."

For women who have come to Canada alone or with only a few family members, separation from this kinship network was particularly stressful. In addition to the lack of family support which most immigrant women had been accustomed to receiving, there was for some an element of shame attached to seeking support outside the family, which in turn created additional barriers to accessing the resources they require:

I have my family that helps. They have my son. I'm not going to rely on assistance forever. This is a shame in my family. I had a very hard time to go through. I was crying days and nights.

SUPPORT

Unfortunately, according to the findings of this study, relatively few caregiving supports exist which transcend cultural barriers or accommodate diverse cultures or related issues such as language, isolation and special economic or educational circumstances. In general, immigrant caregivers described sources of caregiving support as those related

to church groups and community groups. The Metropolitan Immigrant Settlement Association was mentioned by many participants, who claimed that the counselling and educational opportunities they received through that organization were very helpful.

Meeting people, talking about yourself, what's your aim. That really relieves some of the stress.

If I am really down emotionally, I just call my pastor and share my problem.

BARRIERS

Some of the immigrant women who participated in this study experienced extreme social and economic difficulties in their country of origin.

I denied myself anything that could be necessary for a woman because of the war . . . lack of money, because of many bad circumstances.

Although they often perceived life in North America as infinitely more comfortable, this perception acted as a barrier to accessing supports to which they are entitled:

I gave birth; I don't even have to go to the hospital. I had to walk because at that time there was not buses. We don't use these fantastic [disposal diapers]. I still have to wash the nappy.

Language and cultural barriers played a significant role in the socio-economic disadvantage of immigrant caregivers. While the lack of educational and employment opportunities created additional stress, reduced income creates barriers related to transportation and leisure and diminished access to resources for caregiving necessities or to cover costs

related to geo-climate adjustments:

I don't go because I can't afford to have a babysitter.

If you have money, you can go to an entertainment centre. When you have money, you can survive all on your own. You need to get your medication, how [are] you going to see your doctor? How [are] you going to get to that bus? So money speaks all. Because if you have money, you can have your choice.

Yes, it's a combination of work and feeling useful and learning things and having money. But winter is a big deal. It is hard to think about getting out.

Some of us are not adapted to this weather, to the winter weather. You don't want to raise your heat up because it costs more money.

For some of the immigrant parents, the challenges of seeking support multiplied because they were unfamiliar with Canada's policies, regulations, and health care system, as the following participant relates:

When I moved to Canada my experience was hard because I didn't have the language, and because I didn't learn the Canadian system, I was feeling that I didn't have the same abilities as them, and skills. So I was feeling a little bit powerless. . . useless, and because I couldn't provide the cares I should do, or the care I think I thought I should do - because I didn't

have enough knowledge, enough understanding of the systems, and it was...stressful... and also because I don't have friends, my friends, my network, so I had to support that situation, I had to support her just by my own. So the stress of caring for her in an unfamiliar environment without network, support network, was really, is really a frightening situation.

Racism also appeared to be a sensitive issue among some immigrant caregivers. In addition to increasing women's perception of isolation, racial discrimination affected the lives of their children:

I have to go to the school. Children have been beating her a lot and calling her bad names. How is she going to face the hurt? If she is harmed she cannot protect herself.

Finally, some women revealed that cultural insensitivity or a lack of cultural accommodation diminished their capacity to access external resources and supports:

They don't know the language and they don't have the guts to go out. They just feel helpless and isolated at home. "What should I do?" Who will help them, the women?

As immigrant women, I think we need more and more support from the government and from all the resources. We really are limited. . . too little help, too little support. So they are unique, so different really and so much to take care of, so we really need a lot and



have nothing.

The whole system has to develop [something] for immigrants and immigrant women and to give a hand to the women who provide caregiving. Some policy can give more benefit to immigrant families [day care, market tools, social assistance].

Don't underestimate the different cultures. I think there are a lot of differences to address. People think there are a lot of programs and people think that we know a lot of things to manage and move around here and it is not that way.

Women with Disabilities

The focus group discussions conducted with caregivers with disabilities raised a number of issues of significance to them and their experiences with caregiving. These themes were not necessarily new issues; rather they were heightened as compared to the experiences of some of the other caregivers without disabilities:

...I feel when you're a woman you have one strike against you; when you have a disability you have another strike against you. So right away the women in this room now, we have two strikes against [us].

Within this section, three main themes will be examined: the impact of fatigue, the importance of advocacy, and the importance of support and

implications when it is not provided.

THE IMPACT OF FATIGUE

Fatigue was a commonly identified theme within the focus groups for caregivers with a disability. This fatigue resulted (in some cases) both from the disability as well as from the work associated with providing care. The following participant explained her challenge:

I'm on long term disability so I don't have to juggle work but that's its own juggling. I have to juggle with my own fatigue, and things that I have to do. It's a challenge, a big challenge.

For another participant, having a disability affected her sleep patterns and thereby compounded the fatigue she experienced:

Also, depending on the disability you have, doing exercise, if you overdo it, compounds with lack of sleep, because you can't sleep with twitching muscles, or sore back, or pain in your hip, sore knees, whatever. More prone to more illness. Then it takes longer to get well. Loss of sleep. State of mind is also affected by your physical [condition]. Fatigue affects your breathing. Shortness of breath.

Fatigue affected a variety of her experiences and influenced her psychological and physical health.

A woman with a disability and an illness explained that having chronic fatigue syndrome also created challenges when balancing caregiving and unpaid work responsibilities. In her situation, the fatigue she experienced meant that the care she provided to her father,

mother, and son was especially taxing:

I was the prime caregiver for my father who was ill with cancer for two years and at the same time my mother was ill and my father passed away five years ago but my mother has been ill since that time. She has her ups and downs but it's more than a challenge. I'm also a parent but my son is 24 so I don't have to juggle his schedule in that sense. My disability has been visual since I was an infant so I've never really considered that a disability although it obviously is, but now that I have chronic fatigue syndrome. Juggling those two things is more than a challenge in itself.

ADVOCACY

Advocacy and being an advocate for the care recipient was identified by many of the participants as being important; however, for caregivers with disabilities, they also took on this role on their own behalf. Several discussed the importance of “fighting” for their own rights and freedoms to ensure their voices were heard. This need to fight and demonstrate one’s potential was described by a participant who felt it caused her to work harder at her paid employment to demonstrate her skills to others:

Having a disability, we are always trying to prove . . . When they hired me at [fast food restaurant] they told me they would give me a week, and I'd be gone. And within six months I was assistant manager. . . they didn't think I could do it, but you're always trying to prove that you can do it. You

always give that extra 40%. You do and you just go, go, go...just to prove that you can do it because, No. 1, you're a woman; No. 2, you have a disability.

Having to work extra hard may also serve as a factor contributing to the increased fatigue which participants identified or it may be compounding it.

SUPPORT

The need for support was identified by many of the participants in the focus group discussions for caregivers with disabilities. This need was mentioned by other participants without disabilities but may have been of particular importance for those with a disability. Having a support network consisting of family, work colleagues, and friends was seen as necessary for caring. These supports assisted the caregiver in negotiating daily challenges.

Some participants drew upon their family and support network to assist them visually and/or aurally to offset impairments. These members became essentially an extra set of eyes or ears. For example, one woman explained that her son would let her know when the doorbell rang.

Government financial support was identified as a challenge due to the restrictions associated with it. For example, a concern was identified with accessing disability pensions and social assistance. The following participant highlighted her challenges with the system:

When you try to go out to work, they really discourage you. What I told them was, “What you're telling me is I'm better off staying home, on welfare. You can look at it as disability, welfare, whatever, it's all coming from the Province. You're telling me I should stay home, on a cheque, once a month,



600 and some dollars with an eleven year old daughter rather than try and go out and better myself". Our hands are tied.

The challenges this person was experiencing were familiar to another woman. She explained that employers do not always provide drug plans. Not having access to such a plan could be very costly, especially if specific medications were required when living with a disability. As a result, a dilemma was created between deciding to enter (or re-enter) paid employment or to remain on social assistance.

Sometimes when you work, you don't have a drug plan. So, do you stay home and get your medication paid for, or do you go to work? It's a deciding thing for people with a disability.


The final component of support identified by the caregivers with a disability was related to having adequate and appropriate transportation. Some participants received support from friends and family in the form of transportation as needed; however, many participants relied on alternative measures. Few good examples were identified. Many concerns were raised regarding the efficiency and effectiveness of the current public transit system and the expense of using taxis. The following woman highlights her continuous negotiation of the transportation system:

Transportation is a huge issue because I don't drive. Public transit system is terrible, every two hours. Constant worry in the morning, getting to the bus, getting to work or getting a drive, getting my son to babysitter, or arranging someone to come to the house. Am I going to get home on

time?

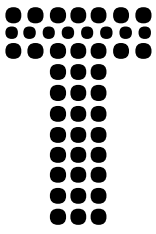
For several of the participants, their disabilities meant that they were unable to drive which meant they had to rely upon other (often unsuitable) transportation sources.

In summary, the themes identified in this section are not completely new additions to the findings; rather they represent issues which were of particular importance for the caregivers with disabilities. In addition, the participants' experiences add a new understanding to the concept which may not have otherwise been obtained. However, it is important to remember that this section does not downplay the importance of any of the other issues in this report which are also significant to caregivers with disabilities.



Chapter 10: Discussion and Recommendations

The variability in caregiving identities and the dynamic nature of caregiving situations pose a challenge for the provision of resources that can assist in providing care.



through the voices of those participating in focus group discussions, this report documents the various situations and experiences of a selected group of individual caregivers in Nova Scotia.

In particular, the situation and experiences of women and men who have traditionally been excluded from research on caregiving, including immigrant women, rural women, women living in poverty, African Nova Scotian women, and First Nations women, individuals caring for persons with HIV/AIDS and sons caring for elderly parents, are included here.

Data from 18 focus group discussions conducted across the province highlight the tremendous variability among individual experiences and situations of caregiving. These data offer insight into the myriad factors that shaped the participants' experiences. Caregiving experiences ranged from the realm of what may be identified as "normative" family interactions and responsibilities, to the provision of complex nursing care. The fact that a single definition of caregiving did not emerge is both a strength and a limitation. What did emerge was an extensive overview of the diversity of caregiving with its multiple meanings and expressions. The strength lies in the breadth of situations that illustrate the caring face of our society. The limitation lies in the fact that such a multitude of care provision manifestations mean that it is difficult to offer simple policy responses to fit such diversity.

So, who are the caregivers? People may not readily identify themselves as caregivers, but rather focus on their relationship role (e.g., wife, mother, partner). The construction of a caregiver identity is dependent on multiple factors, including the professional and educational background, personal qualities and position within the family, and the community of the individual providing care. The construction of a caregiver identity is also strongly shaped by culture and gender expectations. This identity

is not fixed or static. Caring for each other is deeply ingrained in our humanity, a part of our "family and friends membership" (as one participant said: "part of being a woman"), part of how we define ourselves and our relationships with others.

The variability in caregiving identities and the dynamic nature of caregiving situations pose a challenge for the provision of resources that can assist in providing care. Individual abilities to negotiate these resources also vary greatly. For example, the necessity of balancing multiple roles and responsibilities affects an individual caregiver's ability to negotiate access to resources. The presence of other relationships can act as a resource while at the same time the demands of these relationships can limit the ability of the caregiver to access other resources.

The implications of caregiving for caregivers are not uniform. There are, however, some similar concerns expressed about the effects of caregiving among focus group participants. These concerns include the negative effects on leisure time, rest and nutrition and feelings of loss of control over daily life which carry negative implications for health and well-being. The same situations of caregiving that are perceived to negatively affect individual health, however, can also be regarded as rewarding and satisfactory experiences from which a sense of accomplishment and personal satisfaction may be derived.

These findings about the effects of caregiving on individual health are consistent with existing scholarly research that reports high levels of self-reported time stress and an overall decline in leisure time, with implications for health and well-being (Coleman 1999; Phipps, MacDonald & Lethbridge, forthcoming). The highest levels of time stress were reported by women who are employed for pay on a full-time basis and responsible for providing unpaid care to others; unpaid work is not associated with higher

levels of self-reported time stress for men, even when care for both children and the elderly are considered (Phipps, MacDonald & Lethbridge, forthcoming).

Caregiving issues have emerged on the policy agenda in the past fifteen years because the contexts in which we provide care for each other has changed. New policy trends in delivery of health care services; increased life expectancies; changing family configurations; and fiscal restraints have all contributed to new demands on families, friends and communities when providing care to those who need it. However, the widespread variation in the caregiving identity, in caregiving resources and in access to these resources, as well as the impact of caregiving on women and men, can make it not only difficult but often undesirable to enact change by means of uniform policies. No single policy will address all caregiver issues. What is needed are clusters of policies that have underlying assumptions of value for caregiving work and support as defined by the caregiving participants.

Recommendations

Four areas for recommendations related to policy formulation, program design and standards of practice emerge from this study.

Firstly, policies, programs and practices need to take into account the situation of specific caregivers. At a time when there are many different family forms, greater diversity in communities, varying resources in urban and rural settings—it is clear that a “one size fits all” approach will not provide for a situation where caregivers are adequately supported, the caregiving relationship is fostered, and the negative social, health and economic consequences of caregiving are mitigated.

Secondly, women remain the dominant source of caregiving in our society. While many men too participate in various aspects of caregiving,

time use studies consistently demonstrate that women predominate both in the frequency with which they give care, and the quantity of care they provide. Furthermore, different cultural groups require interventions sensitive to their needs. Finally, the accommodations needed by caregivers with disabilities should be specifically defined and provided.

Thirdly, for caregivers in the paid workforce, family-friendly employment policies need expansion and better application in both large and small business sectors.

Fourthly, caregivers need supportive communities, with both physical and social infrastructure required.

All policy and program initiatives need to be considered (and applied) in the context of achieving consistency and fairness across regions. While regionalization emerging from health reform initiatives was intended to respond to communities’ needs for more localized delivery and planning process for services, it has also created some disparities in services and benefits available to people in different regions.

Policy, Program and Practice: The Need for Tailored Responses

The data gathered from these focus groups demonstrate that policies and programs at all levels should have the goal of improved accommodation and response to dynamic and variable

caregiving situations. Explicitly recognizing the needs of caregivers as well as care recipients would enhance the autonomy and individual decision making abilities of both, and reduce stress by providing more control over daily life. Policies, programs and practices should also recognize important differences in culture. Some specific examples where flexibility could be exercised in policy are provided by



individuals and reflect the variability of their caregiving situations. A woman who is living in poverty suggested that greater flexibility in defining what constitutes a “necessity” is needed to care adequately for young children:

[The] phone’s not [considered] a necessity. They don’t qualify that as a necessity. Like, I told her, yes, they are a necessity. If you have a sick child, you need that phone. If there’s an emergency, you need that phone.

One mother of young children felt the tax system should better recognize and reflect the costs associated with caring for young children, while another commented on the difficulty of finding reliable child care.

A further suggestion made by a caregiver is that resource allocation should take caregiver needs into account:

They [caregivers] need you to know what they need, not what you think they need. There is a difference.

More responsive policies, programs and practices affecting caregivers will not only improve the situation of caregivers, with likely improvements for the situation of care recipients, but it can also improve the individual caregiver’s sense of control and individual health and well-being. Enhanced flexibility facilitates the valuing of the caregiving work which has been traditionally undervalued in our society by recognizing the uniqueness of each situation. It accepts that individuals know what they need to sustain themselves and the person they care for. For example, respite offered through a range of services needs to be offered in ways that support rather than limit the caregiver.

Currently, many of the services designed to

support care in the community are ineffective for caregivers because the needs assessment is based so dominantly on the care recipient’s needs rather than the caregiver’s needs. A broadening of the concept of “the client” when determining eligibility for service would make a significant difference for caregivers.

Application of Gender and Equity Lenses

The application of gender and equity lenses in policy is intended to ensure that “all health issues [are] analyzed and determined for their benefits and risks” (Saulnier, Bentley, Gregor, MacNeil, Rathwell & Skinner, 1999). In particular, policies and programs must be assessed for their ability to support a diversity of situations and experiences of caregiving. Given that a disproportionate amount of paid and unpaid caregiving is assumed by women, and that women report greater amounts of time stress associated with balancing the demands of paid and unpaid work, a more rigorous application of gender and equity lenses in policy development and in existing policies is needed. Systemic inequities among women due to race, First Nations status, immigration and disability are reflected in their role as caregivers, and need to be addressed. Policies that reflect only mainstream values and culture need to be examined in the light of diverse cultures and perspectives.

Informed policy, program and practice depends on more precise information about unpaid work, paid work and the efforts of individuals to balance both. Changes to existing data collection tools can enhance understandings of the diversities of caregiving experiences and support the policy and program design process. For example, existing time use surveys should be designed so that findings can be specific to at least the provincial level, and preferably allow for within-province analysis as well to ensure that both rural and urban situations are

considered.

Furthermore, the importance of qualitative research for the understanding and interpretation of caregivers' lived experience can hardly be overstated. While Census and survey data are necessary to grasp the prevalence and incidence of various kinds of caregiving, and its association with a range of demographic, social and economic issues, it is essential to supplement this understanding with the more in-depth understanding that only qualitative approaches can provide.

Application of gender and equity lenses assumes the participation - or voices - of those most affected by the issue. Thus, policy development must ensure mechanisms for participation and feedback by those most likely to be disadvantaged in caregiving situations. Policy and program evaluations are critical to determine policy, program and practice effectiveness and areas for improvement. Such evaluations should be based on the views of both care recipients and caregivers and administered in such a way that respondents can be assured of the confidentiality of their responses.

Family-Friendly Employment Policies

The availability of family-friendly employment policies can be negatively affected by existing attitudes about those who access them. For example, a single mother who spoke about the necessity of having to conceal the stresses of caregiving from her employer illustrates the concern of many women that family responsibilities may limit continued employment and career progression.

There are no set formulae for family friendly employment policies. What is accommodating for one caregiver may be burdensome for other caregiver. The key to the development of family friendly employment policies and practices is the development of a workplace culture that is

supportive of all employees' family needs.

Employment policies will only benefit those who are in the paid workforce, usually in full-time positions. They will not be of benefit to the large numbers of older people caring for their spouses, or those who are providing care over many years for someone with a lifelong disability who may not have been able to be in the paid workforce. There is a "double whammy" in that women are the ones most likely to be caregivers and they are also the most likely to be in low paid part-time or casual positions, the positions which often do not have access to maternity, parental or caregiving benefits which currently depend on eligibility for Employment Insurance. A further concern arises from the fact that women's work patterns, disrupted by family responsibilities, also limit their eligibility for various tax benefits and pension payments. These issues represent important areas for further research.

Supportive Communities

Very significant support to caregivers can be achieved through public policies that support communities.

A recurring theme throughout this study has been the need for better access to transportation. The limitations of accessible bus services, the high cost of other public transportation and private sector initiatives place a significant and growing burden on caregivers, particularly when they themselves are elderly. The Community Links organization has taken the transportation issues for its theme this year, and it is encouraging that the complex issues surrounding transportation and caregiving are being addressed at the community level.

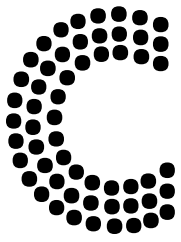
Extensive volunteer services, affordable housing, access to information and training in various media and formats, safe communities, recreation and leisure options, and good education systems all have roles to play in



creating an environment that supports informal caring networks.

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Conclusion



aregiving is as varied as the relationship within which it occurs. Our individual perspectives frame caregiving, as do culture, personal expectations, public policies and values. At the conclusion of this report we return to the beginning of the Healthy Balance Research Program, where Armstrong and Armstrong (2001) emphasized that caregiving should not be construed as a “social problem”. Caring for each other is what defines us as human beings. It is what society is ultimately for, and we need to build a society which takes the provision of care as seriously as it does the market economy.



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Appendices



Appendix A

Healthy Balance Research Program
Research Teams

Secondary Analysis of Existing Data on Caregiving

Analysis of data from the General Social Survey, Cycle 12, to explore the relationship between work hours, paid and unpaid, and stress for Canadian men and women aged 25 - 54, and then to look at the total work hours of women in Atlantic Canada, which are significantly greater than the work hours of woman in other parts of Canada

Focus Groups

Focus groups conducted throughout Nova Scotia, selected by the type of caregiving provided (e.g. childcare, caring for children with disabilities, elder care, caring for sick or disabled adults, and caring for those with HIV/AIDS) as well as from diverse backgrounds, including: rural women, urban women, women living in conditions of low-income, female lone parents, Aboriginal women, African Nova Scotian women, Acadian women, women with disabilities, immigrant women, elderly caregivers, fathers, and sons with elderly parents. The experiences of these groups allow exploration of similarities and dissimilarities between various caregiving experiences as well as the effect on work, family responsibilities and the caregivers' health and well-being.

Population-Based Survey on Caregiving in Nova Scotia

A comprehensive provincial survey of Nova Scotia women and men. A screening questionnaire provides data about the number of Nova Scotians providing care; a more detailed set of questions for those who identify themselves as caregivers provides insight into the scope of caregiving as well as indicate

perceived levels of empowerment, and health outcomes related to caregiving. The survey's capacity to yield a more detailed analysis of the prevalence of various caregiving situations, performed alone and in combination with paid work, among caregivers of diverse racial and ethno-cultural backgrounds, make this the first comprehensive survey of its kind in Nova Scotia.

Caregiver Portraits

Micro-ethnographies of fourteen diverse Nova Scotia households in which care is being provided. Research assistants spend 24 hours in each household as participant-observers and conduct structured interviews. Two households from each of the following communities have participated: Aboriginal, African Nova Scotia, immigrant, caregivers with disabilities, lesbian, rural, and white urban heterosexual. Research assistants are members of the communities in which they are carrying out their observations.



Appendix B

Equity Reference Group Mandate

To ensure active engagement rather than passive acceptance of research processes and products, four Equity Reference Groups have been convened to assist in shaping the details of HBRP research and proposing the most appropriate mechanisms and venues through which to process findings. The five members of each Equity Reference Group will inform the HBRP about particular contingencies traditionally faced by their respective ethno-cultural group. In addition, the Equity Reference Groups will provide advice related to informing policy interventions, program designs, organizational practices and individual choices.

Membership

Each of the Four Equity Reference Groups will consist of five members. Individuals representing Black, Aboriginal, and immigrant women as well as women with disabilities will be invited to participate. Equity Reference Group members may be appointed for a five year term.

Duties

1. Participate in four meetings during the first year of the HBRP and two meetings per year during subsequent years.
2. Recommend and/or approve culturally appropriate methods of data collection as well as recruitment strategies for research participants, interviewers and facilitators.
3. Recommend and/or approve culturally appropriate mechanisms and venues for disseminating HBRP findings to audiences within Black, Aboriginal, immigrant and disabled communities.
4. Identify policy makers, institutions, agencies, groups and individuals for whom

HBRP findings may be relevant.

5. Recommend strategies that will enhance the likelihood of HBRP findings informing policy decisions, program designs, as well as organizational and individual practice.

Decisions

Decisions of the Equity Reference Groups will be confirmed by a simple majority.



Appendix C

A Healthy Balance

A community alliance for health research on women's unpaid caregiving

Question Guide

Introduction:

Caregiving means different things to different people. Some people define it as providing care for sick, disabled or elderly family members, while others use a more broad definition that includes the day-to-day things we do for our family. We are here today to talk about what caregiving means to you and find out how it affects your life and your health.

You don't have to talk about any issues that make you feel uncomfortable and you may stop participating at any time. Once again, we are honoured that you have agreed to help in this study; your input is very valuable.

1. The way we define caregiving and how we experience our role of caregiver may be very different than other people's definitions and experiences. We would like to complete a 'brain storming exercise' to help us understand our different definitions and experiences of caregiving. Please tell us what caregiving means to you so that we can create a chart of some key words regarding caregiving.

Question: When I say the word caregiving what comes to mind for you?

2. Now that we have a sense of the differences and similarities between our understandings of caregiving, we would like to discuss your personal experiences in more detail. We

would like you to share your caregiving experiences with the group.

Question: What are your personal experiences of caregiving?

Probe: Who are you caring for and what type of caregiving do they require?

3. Providing care to another person has likely had impacts on each of you. Some of the impacts of caregiving we can anticipate others we are not aware of until we experience them. The following questions are designed to help us understand the specific ways in which you are each impacted by your role as a caregiver.

Your caregiving experiences may impact your physical health...

Question: How does caregiving impact your physical health?

Probes:

How does caregiving impact the amount of sleep or rest you get on a regular basis?

How does caregiving impact your eating habits and nutrition?

How do you feel that caregiving impacts how often you get sick?

How do you feel that caregiving impacts any medical conditions you have?

4. Caregiving often requires considerable time and effort. Ideally, caregivers are free to choose when they provide care and how much care they provide. However, this is not always the case.

Question: What control do you feel you have over your caregiving responsibilities?

Probes:

How much control do you feel you have over when you provide care?

Describe how you manage the care your

provide?

What situations make it difficult for you to control your caregiving?

How do you decide what caregiving tasks you complete? Provide?

What situations make it difficult for you to control your caregiving?

5. Certain life situations may impact your caregiving experiences. We would like to better understand the circumstances that impact each of you.

Question: How do situations in your life affect your caregiving?

Probes:

Does the area in which you live impact on your experience of caregiving?

How does your ethnic, religious and/or racial heritage and identity help to shape the uniqueness of your of caregiving experiences?

Describe how being a woman/man shapes your experiences of caregiving?

Can you think of any other situations in your life that impact your caregiving?

6. Caregiving experiences may also impact your personal well-being...

Question: How does caregiving impact your emotional well-being?

Probes:

How does caregiving affect your social life?

What feelings emerge when you think of your role as a caregiver?

7. Positive and negative situations bring stress to our lives. Some stress in our life is manageable and necessary; excessive stress can sometimes result in negative effects on

our bodies.

Question: How do your caregiving experiences increase the stress in your life?

Probes:

What resources help you manage any stress you experience through your role as caregiver?

In what way does caregiving bring positives things to your life?

8. Caregiving responsibilities are sometimes combined with other responsibilities and obligations. Caregiving is also combined with our day-to day activities. Caregiving must be balanced with other things we need and want to do. We would like to better understand how you balance your caregiving role with the other roles in your life.

Question:

What effect does caregiving have on your ability to work outside the home?

What effect does caregiving have on your leisure activities?

What effect does caregiving have on your family life?

9. Sometimes people providing care to another person require some assistance.

Question:

What community based and/or government resources assist you with your caregiving experiences?

What personal and family resources assist you with caregiving? (family members, people who share your home, partners etc.)

As a caregiver, what supports would you



like to receive?

Closing:

That concludes our questions. Are there any additional comments, concerns or issues that people would like to share or discuss with the group? We wish to thank you all for participating in the focus group and sharing your experiences with us.

Appendix D

Demographic Statistics Report

TOTAL NUMBERS OF PARTICIPANTS

Total = 107
Female = 98 (91.6%)
Male = 9 (8.4%)

ETHNIC GROUP

Caucasian = 49 (45.8%)
African Canadian = 16 (15.0%)
Immigrant = 13 (12.1%)
Aboriginal = 15 (14.0%)
Other = 14 (13.1%)

COMMUNITY

Rural = 33 (30.8%)
Village = 4 (3.7%)
Small Town = 15 (14.0%)
Town = 18 (16.8%)
City = 31 (29.0%)
Other = 6 (5.6%)

AGE

Youngest (Minimum) = 17 Years
Oldest (Maximum) = 85 Years
Mean Age = 45.61 Years

PAID WORK OUTSIDE HOME

Full-time = 29 (27.1%)
Part-time = 20 (18.7%)
No = 58 (54.2%)

PAID WORK AT HOME

Full-time = 6 (5.6%)
Part-time = 6 (5.6%)
No = 9 (88.8%)

VOLUNTEER WORK OUTSIDE HOME

Yes = 46 (43.0%)
No = 61 (57.0%)

SCHOOL ATTENDANCE

Full-time = 7 (6.5%)
Part-time = 9 (8.4%)

No = 91 (85.0%)

DISABILITY STATUS

Yes = 23 (21.5%)
No = 84 (78.5%)

CARE TIME

Minimum time = 0 years
Maximum time = 71 years
Mean time = 10.9 years

FAMILY INCOME INFO

< \$20,000 = 52 (48.6%)
\$20,000 - \$29,000 = 30 (28.0%)
\$30,000 - \$39,000 = 5 (4.7%)
\$40,000 - \$50,000 = 3 (2.8%)
> \$50,000 = 12 (11.2%)

The Healthy Balance Research Program is a five year exploration of the relationships between women's health and well-being and their paid and unpaid work.

The program of research examines normative unpaid caregiving work throughout the life course, including the provision of care to children, teenagers and adults of all ages.

Four research teams are exploring different aspects of these issues, using methodologies designed to highlight varying facets of the caregiving experience.

Caring for each other is what defines us as human beings. It is what society is ultimately for, and we need to build a society which takes the provision of care as seriously as it does the market economy.

HBRP | Healthy Balance
Research Program

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