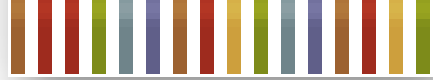


HBRP | Healthy Balance
Research Program

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

A Portrait of Unpaid Care in Nova Scotia

The quality of this document is for screen view only, please do not use for print.



HBRP | Healthy Balance Research Program

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

A Portrait of Unpaid Care in Nova Scotia

Janice Keefe
Glenda Hawkins
Pamela Fancey

With contributions from:

Tasha Ellis

April 2006



Excellence • Innovation • Discovery



© Healthy Balance Research Program

PO Box 745
Halifax, Nova Scotia
B3J 2T3 Canada

Tel: 902-424-7630
Fax: 902-424-0573
www.healthyb.dal.ca

Design: FLAME Design

Printed in Canada

ISBN: 0-9689876-4-8

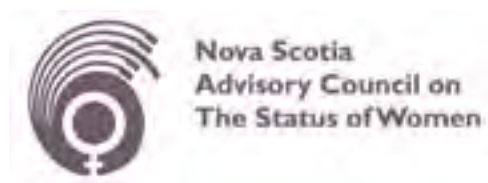
Acknowledgements

We would like to acknowledge the organizations and individuals who have contributed to the Healthy Balance Survey. First, we would like to acknowledge the Healthy Balance Research Program's funder, the Canadian Institutes of Health Research. The research program is led by the Atlantic Centre of Excellence for Women's Health, the Nova Scotia Advisory Council on the Status of Women, and the Institute of Population Health, University of Ottawa.

Second, we would like to express our appreciation to members of the Phase II research team who assisted with the development of the 2005 Healthy Balance Survey: Barbara Clow, Jacqueline Gahagan, Jennifer Jarman, Susan Kirkland, Sheva Medjuck, Brigitte Neumann, Shelley Philips, and Victor Thiessen. We also thank the Population Research Laboratory at the University of Alberta for administering the survey and Brigitte Neumann for her advice and support in developing the contract.

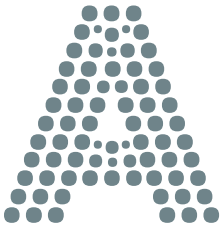
We would like to thank a number of other individuals who contributed to this project: Research Assistants Carla Johnson and Elizabeth Burton for their work on developing the survey and Tasha Ellis and Nadine Brun, for their assistance with the preparation of this report; as well as Healthy Balance team members Cyndi Brannen, Joanne Hussey, and Brigitte Neumann for their review of earlier versions of this report. We appreciate the valuable contribution from all these individuals, but accept full responsibility for any errors or omissions.

Finally, we would like to thank all the Nova Scotians who participated in this survey; because of them we have a better understanding of the caregiving experiences of Nova Scotians.



Executive Summary

We learned in this study that an estimated 36% of Nova Scotians gave care to someone because of a long-term condition, mental illness, or temporary difficult time. The higher prevalence rates of caregiving in Nova Scotia compared to the Canadian rates raise questions about why this occurs and what as a society we are doing to support these caregivers.



s part of a larger program of research, entitled *A Healthy Balance: A community alliance for health research on women's unpaid caregiving*, the Phase II survey of Nova Scotians focuses on the scope of caregiving in Nova Scotia with particular attention to understanding the relationship between caregiving and its impact on the health and economic condition of caregivers and care receivers. This report represents the first in a series of documents presenting research findings.

A telephone survey of English speaking Nova Scotians 19 years of age and older was conducted during winter/spring 2005 on the topic of employment and care responsibilities in Nova Scotia. Data from the Healthy Balance Survey shows that an estimated 36% of Nova Scotians gave care to someone because of a long-term condition, mental illness, or temporary difficult time, 9% reported receiving care, and 58% of the population did neither.

Nova Scotia Caregivers

The profile of men and women caregivers is fairly similar in terms of their socio-demographic and economic characteristics. The majority of caregivers were under 65 years of age, had high levels of life satisfaction and health status, were married or living common-law, lived with others, and were employed in permanent positions. Gender differences are evident in the type and frequency of care provided. Results from the 2005 Healthy Balance Survey indicate that women, who are more likely to participate in caregiving, are also more likely to provide assistance with Activities of Daily Living and Instrumental Activities of Daily Living (ADLs/IADLs). These activities require the highest frequency in provision, while men are more likely to assist with household maintenance and outdoor work. While the majority of men and women caregivers were adult children of the care recipient, men were more likely to be

a spouse of the person for whom they provide care, whereas women comprised a more diverse range of family relationships such as children, spouse and non-immediate family members. The vast majority (70-80 %) of both men and women provided care to an elderly person who received assistance because of a long-term health problem, and did not reside with the caregiver.

Caregiving responsibilities along with employment and family responsibilities can lead to a variety of social, psychological, physical, career, and financial consequences for women who provide care. These consequences may be even greater in situations where caregivers have no support from family, friends, and/or formal services. We learned in this study that almost all men and women caregivers feel that they have someone they can count on for support. However, only around two-thirds of both men and women have someone who can relieve them on a regular basis from caregiving duties. Policies must be developed and evaluated to ensure that they serve both women and men in an equitable manner.

Nova Scotians Receiving Care

Findings from the 2005 Healthy Balance Survey reveal that Nova Scotians who receive assistance, in comparison to the general Nova Scotia population, are older and mostly not employed. They perceive their health to be poorer and are more likely to experience higher levels of stress. These findings have implications for their well-being and that of their families.

For the most part, age grouping and gender were not related to characteristics of the individual receiving assistance or the type of care he/she received. Differences that did emerge between younger and older adults receiving care were younger adults being less satisfied with life, more likely to be married or co-residing with others and, in terms of care provision, receiving more assistance with orchestrating care. This

study did not find associations between gender and other characteristics of care recipients, with one notable exception. Men who required care were more likely than women who required care to be married or living common-law. Given the importance of spousal support for care receivers, this difference is worth further exploration in future research.

Moreover, when examined by age, this group of individuals appears to have distinctive experiences, in terms of who their care providers are, what type of activities they receive, and the reasons for assistance. A greater proportion of younger adults compared to older adults receiving assistance were less satisfied with life, were married or living common-law, lived with others, received assistance because of a health-related temporary difficult time, and relied on immediate family only for assistance. These results suggest the need for further research to broaden the understanding of these differential experiences.

Policy Implications

The higher prevalence rates of caregiving in Nova Scotia compared to the Canadian rates raise questions about why this occurs and what as a society we are doing to support these caregivers. This finding is important because it places the need for adequate caregiver support high on the policy agenda, and

requires particularly that intergovernmental discussion of caregiver support take the greater need in Nova Scotia into account. Moreover, gender differences in the type of care provided reinforce previous research that while both men and women provide care, the type of care that women provides tends to be more intense, more frequent and generally more stressful. The practice of assessing caregiver support needs is of crucial importance, to understand their specific needs and the best ways to support them. The policy implications of these gender differences will be further developed in the reports on the employment and health impacts of caregiving.

The number of individuals receiving assistance is only expected to increase. Population health initiatives may reduce or delay the need for assistance from family and friend caregivers. Ensuring a quality of life for this vulnerable population requires access to a range of supports to reflect the diversity of the experiences of living with chronic illness or disability.

While a full discussion of the policy implications of the survey on caregiving has to await the completion of the subsequent analysis on health and employment issues, this report has identified some possible policy direction to consider. In all cases the implications of any implemented policy must be evaluated using gender, diversity, and rural lens.

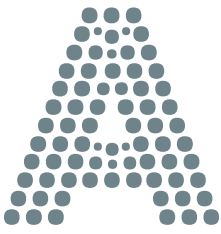
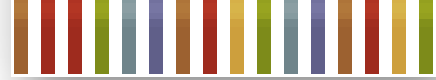


Table of Contents

Executive Summary	ii
Introduction	1
Why Examine Unpaid Care in Nova Scotia?.....	1
Methodology	2
Prevalence of Nova Scotians Giving and Receiving Care.....	2
Summary.....	4
Nova Scotia Caregivers	6
Canadian Caregivers	7
Population-level Profile.....	9
Exploring Gender Differences in Caregiving	12
<i>Socio-demographic and Health Profile</i>	12
<i>Care Provision</i>	13
<i>Care for the Caregiver</i>	17
Nova Scotians Who Receive Care And Assistance	22
Canadian Overview.....	23
Population-level Profile.....	24
Exploring Age Differences among Individuals Receiving Assistance.....	27
<i>Socio-demographic and Health Profile</i>	27
<i>Care Provision</i>	30
Exploring Gender Differences among Individuals Receiving Assistance.....	33
<i>Socio-demographic and Health Profile</i>	33
<i>Care Provision</i>	35
Summary.....	35
Issues For Policy Consideration	36
References	40
Appendices	42
Appendix A.....	43
Appendix B- Research Design.....	45
<i>Telephone Survey</i>	45
<i>Sampling</i>	45
<i>Analysis</i>	45

Introduction

Family and friends provide the majority of care and assistance that individuals with health limitations receive. This care is typically unpaid and provided mostly by women. ... factors suggest an increasing demand for care, yet question the availability and capacity of family and friends as caregivers



Portrait of Unpaid Care in Nova Scotia documents the extent of caregiving by Nova Scotians, the impacts of caregiving, and discusses the implications of these findings for policy makers. This report provides the results of a telephone survey conducted with Nova Scotians in 2005 on the topic of unpaid care. The survey is one component of a larger program of research, entitled *A Healthy Balance: A community alliance for health research on women's unpaid caregiving* (www.healthyb.dal.ca). See Appendix A for details.

This report will complement subsequent reports arising from the Nova Scotia survey on unpaid care and employment and unpaid care and health. This collection of publications will be of benefit to community members, government, voluntary organizations, business, and employers with a goal to inform policy development in Nova Scotia.

WHY EXAMINE UNPAID CARE IN NOVA SCOTIA?

Family and friends provide the majority of care and assistance that individuals with health limitations receive. This care is typically unpaid and provided mostly by women. Today, these realities are challenged by the current socio-demographic context which includes population aging, deinstitutionalization, high labour force participation of women, and migration patterns. These factors suggest an increasing demand for care, yet question the availability and capacity of family and friends as caregivers; a premise upon which most current home care policies are based.

The rates of illness and disease throughout Canada are increasing. In Atlantic Canada, the rates of smoking, obesity and physical inactivity, all of which are associated with chronic diseases and conditions, are above national levels (Hayward & Colman, 2003).

In addition, advanced health care provision, utilization, and technology, contribute to an increased life span for individuals living with permanent disabilities or cognitive impairments. This population with health-related limitations is not only growing in size but in diversity. It is projected that by 2026 almost 1 in 5 Canadians will be aged 65 and over (Cranswick, 2002). Accompanying population aging will be an increase in the number of people living in the community with long-term health conditions.

At the present time there continue to be concerted attempts to provide care for adults with chronic conditions and disabilities in the community. This has been evidenced by efforts to reduce hospital stays and the number of beds available in residential care facilities, and, on average, a higher age of admission to long-term care institutions. These policy shifts contribute to an increased number of individuals, many with complex care needs, requiring care in their homes.

The demand for care and assistance will continue to grow. In order to meet the care needs of individuals, the utilization of family and friend networks and formal (government, private agencies, volunteer) networks will need to increase to adequately address care needs. Family and friend caregivers already play a very significant role in the delivery of care services. However, socio-demographic factors challenge the availability of family and friends as care providers. For example, women's increased rate of participation in the paid labour force results in fewer women to provide necessary care or women trying to balance the demands of work and care responsibilities. One study focusing on projecting the availability of family and friend caregivers in the future found that the use of these support networks will decline, while the use of formal support networks will increase of the next 20 years in Canada (Keefe, Légaré & Carrière, 2005).

In addition, in 2001, Nova Scotia's rural

population comprised a larger share of the total population than was the case Canada-wide (37% compared to 21%). In rural Nova Scotia, high levels of unemployment, few post secondary and limited employment opportunities affect income, health, and well-being. Compared to urban Nova Scotia, rural and small town zones have an older age profile, with smaller proportions of children, youth, and young adults and higher proportions of adults and seniors (De Peuter & Sorensen, 2005). This rural reality presents challenges for those in need of assistance as well as those expected to provide care. Despite these challenges, however, rural Atlantic Canadians are actively engaged in unpaid assistance to others, especially seniors. The proportion of rural Atlantic Canadians providing unpaid housework is slightly less than their national counterparts, but the proportion of rural Atlantic Canadians who provide unpaid care or assistance to seniors is similar (Keefe & Side, 2003). This may be a function of fewer formal services available in rural Atlantic Canada. Moreover, greater proportions of women provide such assistance and devote more hours than do men (Keefe & Side, 2003).

Canadian survey data provides information on unpaid care at a national level. The General Social Survey Cycles 11 and 16 both focus on social support and caregiving. While these surveys are helpful, they do not provide sufficient sample size for analysis of Nova Scotians. As the population in need of assistance increases, it is essential to understand more fully who caregivers and individuals receiving care are and the scope of assistance caregivers currently provide. Therefore, as part of the HBRP, a survey was conducted with Nova Scotians to provide timely information on the scope of caregiving in Nova Scotia with particular attention to the relationship between caregiving and its impact on health and economic conditions. The purpose of this report is to provide an overview of those who participate in caring relationships in Nova Scotia from the perspective of both

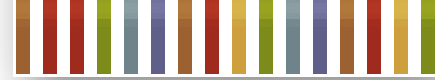
those giving and/or receiving care. This report not only raises awareness about the state of unpaid care in Nova Scotia, but also identifies issues requiring policy attention.

METHODOLOGY

Data presented in this report were obtained from a stratified telephone survey of the NS population conducted in the winter/spring of 2005. The sample in the first part of the Survey consisted of 1,988 English-speaking Nova Scotians 19 years of age and older. The sample is comparable to the NS population as reported by the 2001 Canadian Census (see Appendix B). Only those individuals who indicated they gave and/or received care in Part I were invited to participate in Part II. The sample for Part II was also stratified on the basis of give/receive care, rural/urban residency, and male/female. To ensure equal representation by gender and to strengthen comparative analysis, males were over sampled. Part II was completed by 465 respondents. The response rate for Part I was 42% and for Part II was 74%. Detailed information on the sample, comparison with the Nova Scotia population as reported by the Census and definitions used in this report are presented in Appendix B.

PREVALENCE OF NOVA SCOTIANS GIVING AND RECEIVING CARE

Consistent with findings for unpaid work, many Nova Scotians are caregivers. The Healthy Balance Survey demonstrates that in 2005 an estimated 36% (265,693) of Nova Scotians gave care to someone because of a long-term condition, mental illness, or temporary difficult time. Approximately 9% (65,768) of Nova Scotians reported receiving care because of a long-term condition, mental illness, or temporary difficult time. Over half of the Nova Scotia population (58% or 423,961) did not participate in giving and/or receiving care (Figure 1).

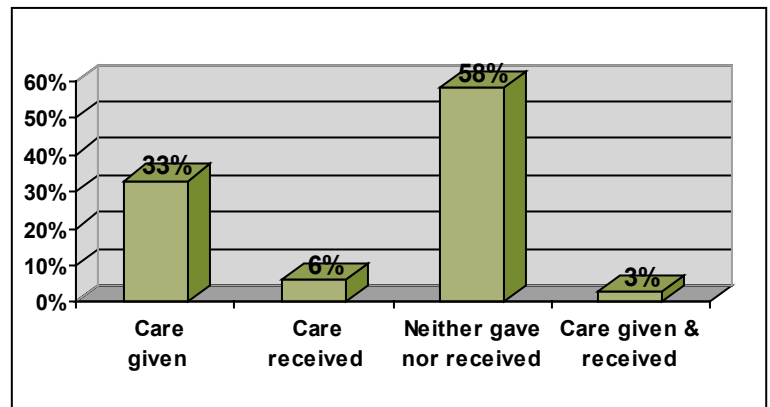


Despite similar methodologies (e.g., telephone survey), research foci, and questions between the Healthy Balance Survey and General Social Survey, the proportion of Nova Scotians giving care is considerably higher than findings at the national level almost 10 years earlier, where in 1996 only 11% of Canadians aged 15 and over were involved in informal caregiving because of a long-term health problem (Keating et al., 1999). This variation in proportions may be partially attributed to differences between the two surveys in age criterion, definition of caregivers, and/or caregiver bias in response rates.¹ The time lag of 10 years will also have an influence – other research demonstrated that the proportion of the population who provide care is increasing over time at least partially attributable to population aging (Keefe & Side, 2003). In a comparison with more recent data, namely the 2002 General Social Survey, a similar trend is found. Among caregivers aged 45 and older, about 20% provide care to an older Canadian (aged 65 and older) because of a long term health problem compared to a comparable subset of the Healthy Balance Survey data of 32%². The higher proportion of women caregivers in Nova Scotia echoes Lethbridge and colleagues findings that women in Atlantic Canada were more likely to be caregivers than other Canadian women (Lethbridge et al. 2005). This higher prevalence of caregivers in Nova Scotia may be due in part to Nova Scotia having the second-highest proportion of individuals 65 years of age and older, high disability and chronic illness rates, and a high proportion of residents in rural areas where extensive formal services may be less readily available.

The proportion of Nova Scotians who stated that they received care in the 12 months prior to the survey seems to be somewhat low (9%). Comparing these findings to statistics

Figure 1

Proportion of Nova Scotians 19 years of age and older engaged in caring relations. (Adjusted weights; $n = 1988$)



reported in other studies is difficult given differences in survey samples. In 2001, more than three million Canadians aged 15 and over, representing 12% of the Canadian population, were limited in their everyday activities due to a physical, psychological, or health related condition or problem (Statistics Canada, 2004). In 1996, the majority of Canadians (80% of non-seniors and 73% of seniors) living in the community reported receiving assistance with their everyday activities. However, when looking at the reason behind needing assistance, only 3% of non-seniors and over 20% of Canadian seniors needed assistance because of a long-term health problem or physical limitation. In 2001, this senior population represented around 1 million Canadians.

The ratio of caregivers to those who receive care estimated from this survey is high – suggesting four caregivers for every person who receives assistance with care. Possible explanations for the higher incidence of caregivers are listed in the above paragraph. Several factors may account for the lower prevalence of Nova Scotians who receive care. First, individuals may not self-identify themselves as care recipients,

1. The Healthy Balance Survey age cut-off was 19 years, and caregivers who were providing care because of long-term health problems or temporary difficult times were included. In the 1996 General Social Survey the age cut off was 15 years, and Statistics Canada reports generated thus far, have only examined those who provided care because of long-term health problems, whereas the Healthy Balance Survey includes those caring for others due to temporary difficult times.
2. The estimate using Healthy Balance data includes individuals who provide assistance with temporary difficult times and a factoring applied to the subsample of 45 and older caregivers to limit the comparison group to care of older Nova Scotians (aged 65 and older).

individuals receiving care may be less likely to answer the phone or agree to be interviewed due to the severity of health limitations, and individuals receiving care represent a small proportion of the population in general so they are harder to access using random techniques. Also, a large number of individuals with activity limitations and health problems either do not need assistance or else simply do not receive assistance. They have either made adaptations and can live independently without assistance from others, they may not need or want care, or else do not know how to obtain it.

Around 3% of Nova Scotians participated in both giving and receiving care. This represents a very unique group of individuals characterized by a higher proportion of women, rural residents, and individuals less than 65 years of age (75%). Unfortunately, the sample size is too small for any reliable analysis.

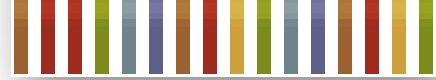
SUMMARY

The remainder of this report is organized into 3 sections, with focuses on Nova Scotians who give care, those who receive care, and implications for policy, respectively. The first two sections begin with a brief review of current knowledge to understand the caregiver and care recipient population within the context of national level results. One section highlights gender differences among caregivers in Nova Scotia, while another section explores in greater detail how Nova Scotians who receive care differ by age and gender, according to individual, living context, socio-economic status, and care provision characteristics. The final section presents the implications of key findings from previous sections for policy makers within provincial and federal governments and key stakeholder organizations.



Nova Scotia Caregivers

Gender differences in the type of care provided found in our study, reinforce previous research that while both men and women provide care, the type of care that women provide tends to be more intense, more frequent, and generally more stressful



his section focuses on Nova Scotians who provided care, attention, or other forms of assistance for any individuals who have a long-term condition, mental illness, are experiencing a temporary difficult time or who were ill, frail or disabled within the last 12 months. First, current knowledge about caregiving is provided. Next, a comparison of Nova Scotians who are caregivers and who are not is presented, using statistics weighted to reflect the population. Finally, a sample of 409 Nova Scotia caregivers is analyzed by gender to show distinctive differences in the caregiving experience for men and women.

CANADIAN CAREGIVERS

In 1996, 11% of Canadians 15 years of age and older provided care to someone because of a long-term health condition (Keating et al., 1999). According to results from the 2002 General Social Survey, 20% of Canadians aged 45 and over were providing care to a senior (aged 65 and over) – almost 2.4 million (Fast, 2005). These studies have also shown that caregivers tend to be female, married, employed, have at least high school education, and live in urban areas (Fast, 2005).

Caregiving, while often limited to the context of eldercare, includes the provision of assistance to children, youths, and adults of working age with short or long-term health problems or limitations. In 2001, family caregivers in Canada provided assistance to nearly one million individuals between the ages of 16 and 64 with a long-term health condition (Roeher Institute, 2003). Sixty-nine percent of caregivers to adults with disabilities were aged 45 and under (Roeher Institute, 2003). The majority of these caregivers were parents or partners (74%), followed by sons, daughters, or siblings (17%). It is important to note that over time, caregivers can change, especially in the situation of adults with lifelong disabilities. Initially, parents are most likely to assume

caregiving responsibilities from birth or the onset of disability. However, when parents are no longer able to provide care because of death of a parent(s), or if the progression of disability is more than they can handle due to their own health status in later life, care may then fall to siblings or formal support services.

When examining literature around care provision to seniors, spouses are more likely to be primary caregivers followed by daughters, daughters-in-law, and sons. Siblings who live close by are more likely to help with Instrumental Activities of Daily Living (e.g., transportation, shopping) than with personal care. Similarly, other family members such as nieces, nephews, and cousins are less likely to help and the help they do provide tends to be with transportation and grocery shopping, but not personal care (Chappell, 1992; Keating et al., 1999).

Caregivers provide assistance to people of various ages and levels of disability. On average, Canadians provide care to more than one individual at the same time, for just over two years. Most commonly, caregivers live near the elderly person they provide care for, and few live with the care recipient (Cranswick, 2002; Keating et al., 1999). Residency patterns and proximity to individuals who receive care are important characteristics to examine; especially in Nova Scotia where close to 40% of the population consists of rural and small town residents (De Peuter & Sorensen, 2005). In 1996, 25% of Canadian caregivers 15 years of age and older lived in rural areas. Most rural caregivers are between the ages of 30 and 49, are married or in a common-law relationship, live with others, and have no children (Keating et al., 1999). Rural communities often have limited resources and services. As migration to urban areas increases, the need for both caregivers and formalized services in rural areas will increase.

Family and friend caregivers play a significant

role in the delivery of care and assistance. They provide an estimated 70% to 80% of the care to disabled seniors living at home (Hébert et al., 2001). Similarly, Lafrenière and colleagues (2003) found that family and friend caregivers spend proportionately more time providing care than formal providers. In fact, more than 70% of the hours of services provided to disabled seniors were attributed to family and friends.

Caregivers to younger or older adults with disabilities assist with the provision of a range of activities, including, but not limited to activities inside the home (cleaning, meal preparation, laundry), outside the home (house maintenance, outdoor work), transportation, banking/bill payment, shopping, care management, and personal care (bathing, toileting, hygiene) (Cranswick, 2002; Statistics Canada, 2004).

The Gendered Nature of Care

Women are predominantly the caregivers to seniors at 61% compared to 39% of men (Keating et al., 1999). Furthermore, adult daughters assume the greater amount of caregiving responsibility towards parents (Guberman & Maheu, 1999; Keating et al., 1994).

Gender differences in caregiving become most visible when type of care provided is examined. Women are also predominantly involved in the most time-consuming and demanding activities: household chores and personal care. A greater proportion of men provides house maintenance and repair which were less time demanding (Fast, 2005; Keating, 1999). On average, Canadian women are providing in total, more hours of paid and unpaid work than men. Regional differences exist in the amount of time devoted to paid and unpaid work; women in Atlantic Canada provide over 80 hours/week compared to women in the rest of Canada who provide around 73 hours/week (MacDonald et al., 2005). Furthermore, differences between rural and urban communities exist; a greater

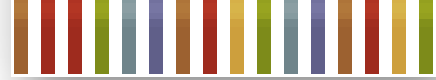
proportion of women provided unpaid care or assistance to seniors compared to men in rural Atlantic Canada (Keefe & Side, 2003).

The gender differences in caregiving are important because women are also more likely to assume family responsibilities including unpaid childcare and housework which can have social, physiological, physical, and economic implications (Lethbridge, MacDonald, & Phipps, 2005; Sawatzky & Fowler-Kerry, 2003).

Impacts of Caregiving

Most caregivers agree that their caregiving experience has both positive and negative aspects. In 2001, around 80% of caregivers recognized the intrinsic rewards associated with providing care – giving back and strengthening the relationship between the caregiver and the person to whom they provide care (Cranswick, 2002). However, many caregivers experience negative consequences associated with providing care. Social and psychological consequences include burnout, stress, and perceived burden. Physical injury may occur, through heavy lifting and stress-related conditions such as hypertension. Economic consequences may include job disruption, inability to accumulate pension credits, and high out-of-pocket costs associated with caregiving in the home. Cranswick (2002) found that one-third of caregivers to seniors incurred extra expenses, 1 in 10 had health problems associated with providing care, including sleep deprivation, and a significant number reported labour market interruptions.

Interestingly, a higher proportion of women reported experiencing labour market interruptions compared to their male counterparts. The proportion of women caregivers between the age of 45 and 54 who had to change their work patterns was twice that of male caregivers (Cranswick, 2002). The distinctive work patterns of women are intimately connected to gender role expectations



that perpetuate assumptions about women as “natural nurturers” who ought to place priority on providing care as opposed to concentrating on their career. Women indicate more work and family conflict in terms of their caregiving responsibilities than men (Kramer & Kipnis, 1995). Women who do work have more competing demands placed on them as they try to balance family, work, and caregiving (Gahagan et al., 2004). The continual imbalance resulting from inadequate support, will not only result in further stress and burden on women caregivers, but continue to disadvantage them in the labour market.

Sawatzky & Fowler-Kerry (2003) note that caregiving can affect personal identity, adapting and coping, and health. Caregivers must often reconfigure their personal lifestyles and work lives in order to provide care with associated long lasting impacts.

Availability of Caregivers

Over the last few years many factors have affected the availability of caregivers to provide care within the home. Factors such as increased labour force participation rates of women, life expectancy, divorce rates, reconstituted families, sandwich generation families, geographical mobility, and a decrease in fertility rates are critically questioning the availability of caregivers, especially women, who already take on the bulk of caregiving responsibilities, to continue in this role. Caregivers of adults with disabilities also face additional challenges due to diminishing health, income, and social support as they age. These factors have challenged and continue to challenge the caregiver’s ability to provide essential care. It is important to understand caregiving as it exists now in Canada and in Nova Scotia, so that we can prepare to meet the needs of caregivers in the future and ensure their sustainability in the long-term.

There is still much to learn and understand

about who caregivers are, especially in Nova Scotia. Given the potential impact of future demographic and health characteristics, it is necessary that we understand who caregivers in Nova Scotia are and how they differ from other Nova Scotians who do not participate in caregiving activities. Given the significance that gender plays in the provision of care, this analysis will further explore how women and men who provide care differ on individual, living context, socio-economic, and care provision characteristics in an effort to determine the key implications for policy makers within Nova Scotia.

POPULATION-LEVEL PROFILE

Using Healthy Balance Survey data, a comparison of Nova Scotia caregivers to non-caregivers according to individual characteristics, residency and paid labour force participation are displayed in Tables 1, 2, and 3 respectively.

Individual Characteristics

Table 1 illustrates the differences between those who give care and those who do not. Women in Nova Scotia made up the majority of caregivers (56%), although, a significant proportion of men (44%) were also involved in giving care to persons because of long-term health problems or a temporary difficult time. Women and men differed in terms of the type and amount of caregiving they do. These differences are examined in more detail later in this section. Only 12% of caregivers were aged 65 and over, compared to almost 20% of non-caregivers in the same age group. In other words, a greater proportion of Nova Scotians who provided care, compared to those who did not, were under the age of 65. This population also faced other responsibilities, such as employment and childcare.

Nova Scotians with and without caregiving responsibilities reported similar levels of life

satisfaction and health status (Table 1). They differed however in self-reported stress. A higher proportion of Nova Scotia caregivers compared to non-caregivers experienced higher levels of stress (27% compared to 19%).

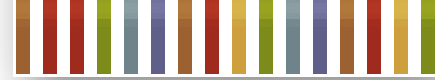
Table 1. Individual characteristics by caregiving status. (Adjusted weights; $n = 1988$)

	Caregivers $n = 723$ %	Non-Caregivers $n = 1266$ %	Chi-Square χ^2
Gender			
Women	56	49	8.2**
Men	44	51	
Age			
19-44	43	51	41.7***
45-64	45	31	
65 +	12	18	
Perceived health status			
Excellent/very good	59	58	.32
Good	26	27	
Fair/poor	14	15	
Life satisfaction			
Very satisfied	47	49	.57
Somewhat satisfied	43	42	
Somewhat/very dissatisfied	10	10	
Level of stress			
Not at all/not very stressful	30	37	17.5 ***
A bit stressful	44	44	
Quite a bit/extremely stressful	27	19	

* $p < .05$, ** $p < .01$, *** $p < .001$.

Residency

There was no significant difference in the proportion of caregivers who lived in rural and urban areas compared to non-caregivers, with just under half of both groups living in rural communities (Table 2). The availability of formal support and services in rural areas is often limited compared to urban areas. This suggests that family and friends may be relied on more in rural communities to fill this gap, however this was not consistent with our



findings. It is, however, important to note that we are describing the location of caregivers; even though caregivers may live in urban areas, they may be traveling to rural areas to provide care. This relationship is examined later in this section.

Paid Labour Force Participation

For the most part, caregivers were distinguished from non-caregivers on the basis of paid labour force participation (Table 3). Despite the often-demanding nature of providing care, a high proportion of caregivers worked in the paid labour force. Similar to non-caregivers,

almost half of caregivers worked full-time. A lower proportion of caregivers compared to non-caregivers reported being non-employed (Table 3). There was a slight difference in the proportion of caregivers and non-caregivers working in permanent positions, 68% compared to 75% respectively. Although caregivers may be somewhat similar to non-caregivers in terms of their employment, interruptions such as reduced hours, distractions, and passing up opportunities may be greater among caregivers. A detailed analysis of employed caregivers and their costs and consequences of combine employment and caregiving will be examined in a subsequent report.

Table 2. Location of residence by caregiving status. (Adjusted weights; $n = 1988$)

	Caregivers $n = 723$ %	Non-Caregivers $n = 1266$ %	Chi-Square χ^2
Residency			
Urban	51	53	.96
Rural	49	47	

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 3. Labour force participation by caregiving status. (Adjusted weights; $n = 1988$)

	Caregivers $n = 723$ %	Non-Caregivers $n = 1266$ %	Chi-Square χ^2
Employment			
Not employed	41	47	7.7*
Employed full-time	47	45	
Employed part-time	12	9	
Type of employment of full-time & part-time employees			
Permanent	68	75	6.9*
Casual/contract/seasonal/other	20	15	
Self-employed	13	10	

* $p < .05$, ** $p < .01$, *** $p < .001$.

This profile of caregivers at the population-level portrays a group of individuals, mostly women, who in addition to caregiving responsibilities balance employment, mostly full-time and permanent, with their other family responsibilities. The focus of the next section will be on understanding how women and men differ as caregivers.

EXPLORING GENDER DIFFERENCES IN CAREGIVING

This section will highlight findings from a gender comparison of Nova Scotia caregivers according to individual characteristics, living context, paid labour force participation, care provision (including geographic location, activities, and frequency of provision), and care for the caregiver.

Socio-demographic and Health Profile

Individual Characteristics

There were no significant gender differences amongst caregivers on age, health status, life satisfaction, or stress (Table 4). About half of men and women caregivers were between the ages of 45 and 64. The majority of both men and women caregivers perceived their health status as excellent or very good and were satisfied with life. However, over one-quarter of men and women caregivers felt very stressed.

Living Context

As shown in Table 5, around three-quarters of men and women caregivers were married, but a greater proportion of women were widowed compared to men (9% compared to 2%). This

Table 4. Individual characteristics of caregivers by gender. ($n = 409$)

	Men $n = 176$ %	Women $n = 233$ %	Chi-Square χ^2
Age			
19-44	33	39	1.7
45-64	53	50	
65 +	14	12	
Perceived health status			
Excellent/very good	57	61	1.12
Good	26	22	
Fair/poor	17	17	
Life satisfaction			
Very satisfied	47	51	2.6
Somewhat satisfied	41	42	
Somewhat/very dissatisfied	13	8	
Level of stress			
Not at all/not very stressful	33	27	2.4
A bit stressful	38	45	
Quite a bit/extremely stressful	29	28	

* $p < .05$, ** $p < .01$, *** $p < .001$.



Table 5. Living context characteristics of caregivers by gender.³ (n = 409)

	Men n = 176 %	Women n = 233 %	Chi-Square χ^2
Marital status			
Married/common-law	74	74	9.4*
Divorced/separated	11	8	
Widowed	2	9	
Never married/single	12	9	
Living arrangement			
Living alone	13	11	.4
Living with others	87	89	
Length in community			
0-3 yrs	10	14	1.1
4+ yrs	90	86	

*p < .05, **p < .01, ***p < .001.

finding has implications in terms of available support for women in their caregiving role. Many wives provide care to a husband prior to his death, and then, as their own health status deteriorates, they may continue to provide care for other family members or neighbours/friends despite finding themselves with very limited social and economic resources to support their caregiving role. The majority of caregivers lived with others, with only 13% and 11% of men and women caregivers, respectively, living alone. Most of the caregivers in this survey have lived in their community for four or more years.

Socio-economic Status

Men and women caregivers differed on several socio-economic status characteristics. As in the total population, male caregivers were more likely to work full-time, while women were more likely to work part-time. Twenty percent more men than women caregivers were employed full-time (Table 6). This has major implications for women. First, women are less likely to be able to access support benefits, pension plans, and higher wage, as

these are usually key characteristics of full-time employment. Second, they have lower incomes from which to access resources on their own. No differences were reported in the proportion of men and women caregivers with permanent positions. Not only were women slightly less likely to be employed, but also women were more likely to hold part-time and casual positions than their male counterparts. The education and household income of men and women caregivers did not differ significantly.

Care Provision

Providing Care

The vast majority of men and women caregivers in Nova Scotia, as shown in Figures 2 and 3, provided care to an elderly person and provided assistance to someone because of a long-term health problem. Meeting the needs of this population may be very demanding, as their care responsibilities will likely continue over an extended period of time. Almost 50% of both men and women were adult children providing care to an elderly parent. Because many were

3. Residency was not included in this analysis, as findings would be a direct result of stratification techniques using gender and rural/urban residency.

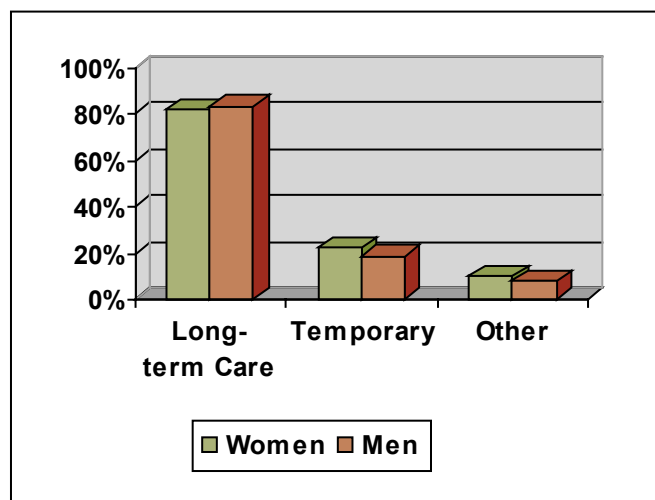
Table 6. Socio-economic characteristics of caregivers by gender. (n = 409)

	Men n = 176 %	Women n = 233 %	Chi-Square χ^2
Education level			
< High school	13	11	7.9
High school diploma	17	18	
Some college or university	15	24	
Diploma/certificate	19	22	
At least post-secondary	36	26	
Employment			
Not employed	42	47	25.9***
Employed full-time	54	34	
Employed part-time	5	20	
Type of employment			
Permanent	64	66	1.1
Casual/contract/seasonal/other	19	22	
Self-employed	17	12	
Household gross income			
\$0-\$19,999	9	11	5.9
\$20,000-\$39,999	18	25	
\$40,000-\$59,999	24	27	
\$60,000 +	50	37	

*p < .05, **p < .01, ***p < .001.

Figure 2

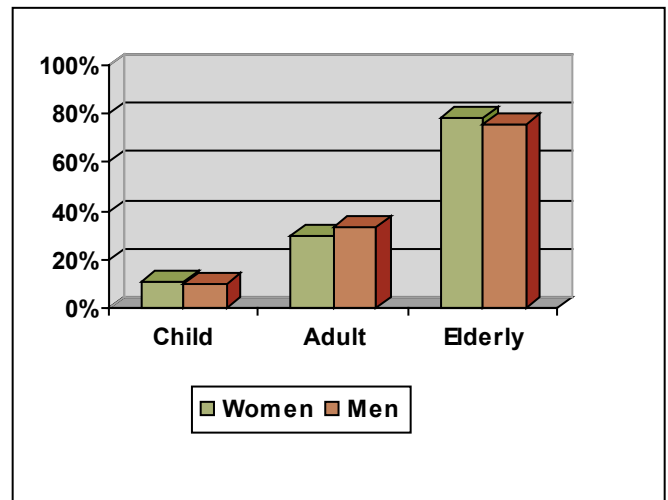
Proportion of caregivers providing care by reason.



Note: percentages do not total 100% due to multiple responses

Figure 3

Proportion of caregivers providing care to children, adults, and elderly persons.



Note: percentages do not total 100% due to multiple responses



adult children providing care, they were also more than likely balancing these caregiving responsibilities with employment and other responsibilities. Gender differences existed in that men were more likely to provide care to a spouse, and women were more likely to provide care to other family members⁴ (Figure 4). These differences reflect national trends, in that women caregivers tend to engage in a series of caregiving activities, first for children, later for elderly parents and other family members, and eventually for their spouse. Male caregivers, on the other hand, are more likely to be a spouse or immediate family member. Since older women have more years of life with various disabilities, if their spouse is living, it is these spousal caregivers who are more likely to provide the necessary care.

Geographic Location and Caregiving

As shown in Figure 5, the majority of both men and women caregivers provided assistance to someone living outside their home only (over 60%). Care recipients are choosing to age in place, and to enable this, support policies must be in place for care recipients as well as caregivers, who may travel long or short

Figure 5

Proportion of caregivers providing care to persons who reside inside and/or outside the caregiver’s home.

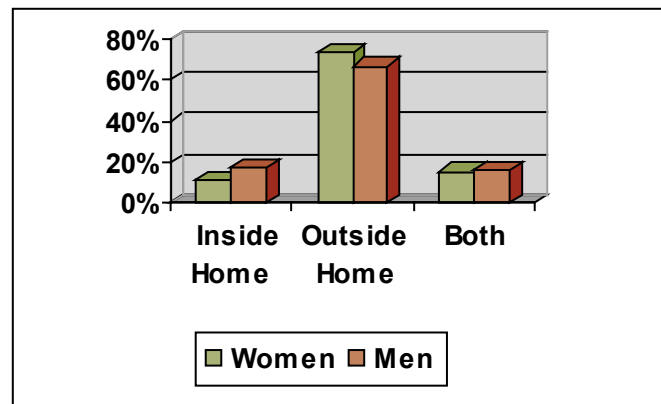
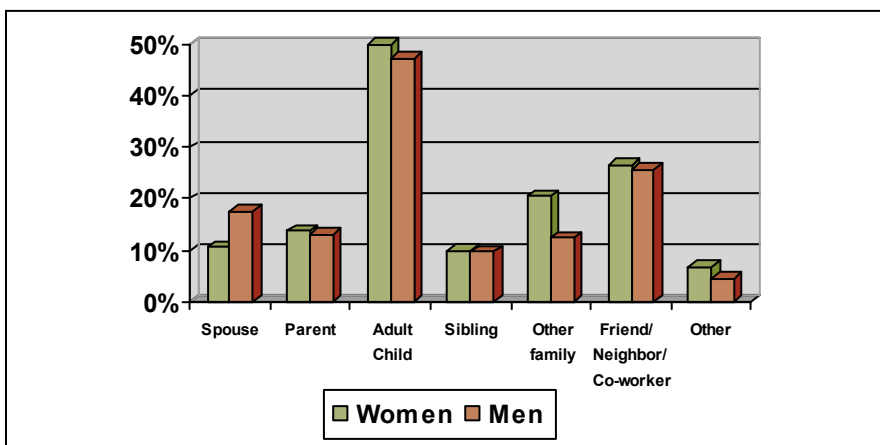


Figure 4

The relationship of caregivers to the person for whom they provide care.



Note: percentages do not total 100% due to multiple responses

4. Other family members include grandparents, grandchildren, cousins, aunts, uncles, nieces, and nephews.

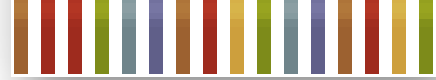
Table 7. Percentage of caregivers (not in same household) who travel this amount of time (one-way) from their residence to the individuals they provide assistance for, by location of caregiver's residence. ($n = 286$)

	Urban $n = 107$ %	Rural $n = 179$ %	Chi-Square χ^2
Up to 15 minutes	58	67	3.4
16-30 minutes	29	13	12.3***
31-59 minutes	5	8	1.3
1 hour or more	16	17	.1

* $p < .05$, ** $p < .01$, *** $p < .001$.

Table 8. Major categories of activities by tasks.

Activities	Tasks
Activities of Daily Living (ADLs) /Instrumental Activities of Daily Living (IADLs)	Cleaning house Doing laundry Preparing meals, cleanup Personal care Check on individual receiving care at night
Psycho-social support	Checking up on others Reassure individual receiving care Get person to participate in activities Providing emotional support
Facilitation/ Supervision	Interpret for individual receiving care Organize/train support workers Prevent injuries/wandering Stay in house so individual feels safe Improve relations between individual receiving care and others Change unwanted behaviors
Orchestrating care	Monitoring services Locating services Arranging appointments Arranging transportation Banking and paying bills
Transportation/ Shopping	Providing transportation Accompanying to appointments Shopping for groceries/ other items
House Maintenance/ Outdoor work	Doing house maintenance Outdoor work



distances to provide care. Of those providing care to someone outside their home, there were no significant differences in the proportion of men and women living within designated time intervals to those for whom they provide care (Table 7). Over half of men and women caregivers provided care to someone who lived within 15 minutes of their home. Although the majority of caregivers did not live with the individual receiving care, they were still reasonably close to the people for whom they provided care. Over 15% of both men and women caregivers, however, lived at a considerably distance, over an hour, from the care recipient. This geographic distance may affect the type of activities with which they provide assistance, the amount of care provided, or both. This analysis is limited in that it does not include the cumulative amount of time spent traveling to all care recipients. Additional analysis will need to examine the amount of distance by the frequency with which the caregiver provided assistance. Previous research has highlighted the challenges many caregivers face when their home, that of the care recipient, and their workplace take them in three different directions (Joseph & Hallman, 1996).

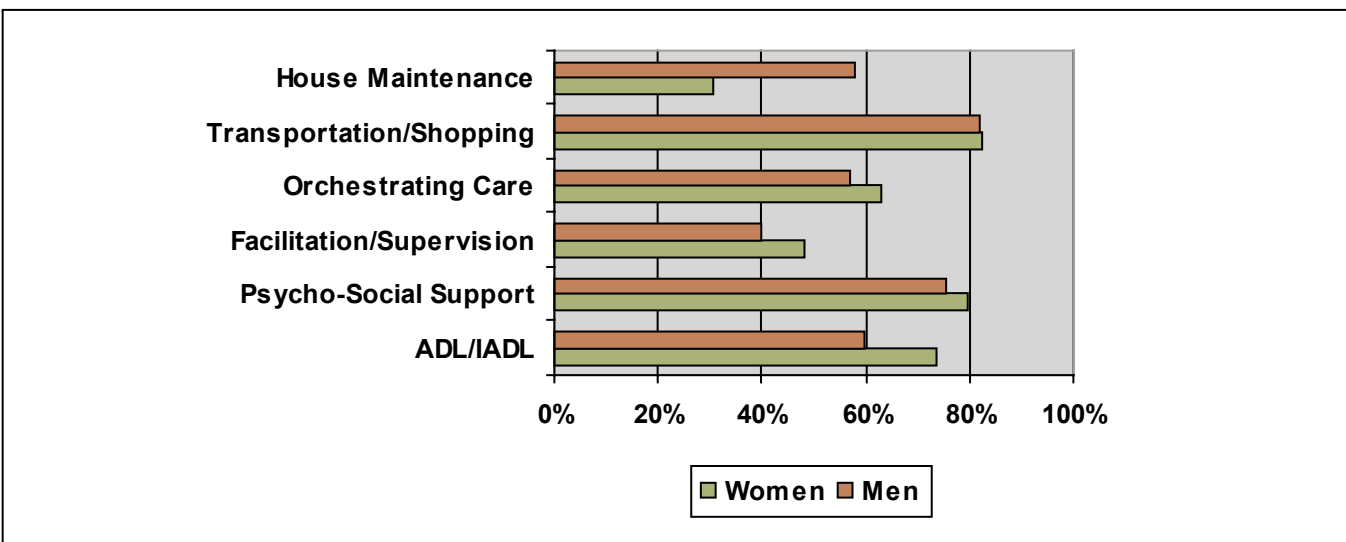
Do caregivers in urban areas travel to rural areas, presumably where their parents live, to provide care? As shown in Table 7, rural and urban caregivers, for the most part, do not differ in travel time to their care recipient except for those who are at least 16-30 minutes away from the person they provided care. In this case, a significantly greater proportion of urban caregivers were traveling within 16-30 minutes to provide care. This may reflect individuals driving out of the urban core to provide care to family members in nearby rural areas or it could be that greater travel time is a function of urban life (e.g., traffic congestion).

Activities and Caregiving

In order to describe the varied activities that caregivers assist with, more than 20 individual tasks were grouped into six major activity categories (see Table 8).⁵

Figure 6 shows that the most common activities that men and women caregivers provided assistance with were transportation and shopping (82% each) followed by psycho-social support (80% of women versus 76% of men). Both Nova Scotia men and women caregivers were less likely to provide assistance with house maintenance and facilitation/

Figure 6
Proportion of caregivers providing assistance by type of activity.



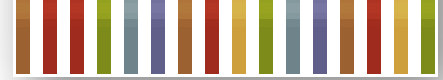
5. A Principal Component Analysis using varimax rotation of 25 activities was conducted on the sample of caregivers, yielding 6 factors with eigen values greater than one.

Table 9. Frequency of activity provision of caregivers by gender. ($n = 409$)⁶

	Men <i>n</i> = 176 %	Women <i>n</i> = 233 %	Chi-square χ^2
Total tasks			
Less than weekly	17	12	1.9
Weekly-daily	31	29	
More than daily	52	58	
ADL/IADL			
None	38	24	9.6*
Less than weekly	11	16	
Weekly-daily	24	26	
More than daily	27	34	
Psycho-social support			
None	22	18	6.6
Less than weekly	13	15	
Weekly-daily	35	26	
More than daily	31	42	
Facilitation/Supervision			
None	59	50	9.9*
Less than weekly	9	20	
Weekly-daily	18	14	
More than daily	15	16	
Orchestrating care			
None	41	35	2.6
Less than weekly	30	38	
Weekly-daily	20	19	
More than daily	9	8	
House maint./outdoor work			
None	40	69	32.5***
Less than weekly	32	17	
Weekly-daily	24	12	
More than daily	4	3	
Transportation/shopping			
None	15	15	1.8
Less than weekly	38	37	
Weekly-daily	35	40	
More than daily	12	8	

* $p < .05$, ** $p < .01$, *** $p < .001$.

6. These data are not standardized and are based on factors identified in factor analysis. The frequency of activity provision is in part resulting from the number of tasks included within each activity.



supervision compared to the other activities. There were significant gender divisions within the delivery of two of these activities. First, a greater proportion of women provided assistance with ADLs and IADLs (cleaning, laundry, personal care, etc.) than men. Men, on the other hand, were more likely than women to provide assistance with outdoor work and household maintenance. These findings are consistent with gender divisions of caregiving at the national level (Cranswick, 2002; Fast, 2005).

The frequency in which activities were provided differed according to gender. Not only did a greater proportion of women provide ADL/IADL activities, but these were also the most frequently provided activities, with over one-third of women providing more than one of these tasks on a daily basis (Table 9). The nature of ADL/IADL activities and the

frequency in which they are provided suggests that the individual receiving care has high care needs. Providing care to individuals with high care needs will only make caregivers more prone to greater stress as they balance work and family responsibilities with spending more time providing care activities. Traditional gender differences are also evident in men being more frequent providers of outdoor work and household maintenance compared to women but in this case, the frequently tends to be on a weekly basis rather than daily as in the case of ADL/IADL activities. This raises serious consequences for women since their care work tends to be more intense, more frequent and more stressful than men's care work.

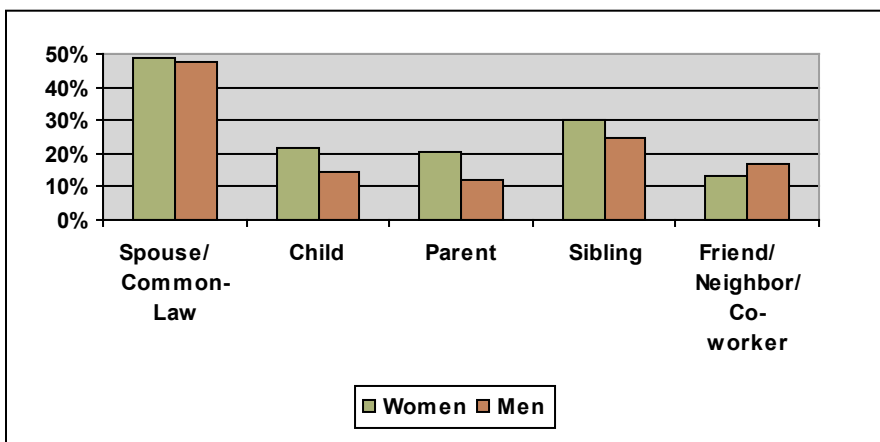
Care for the Caregiver

In terms of support, around 91% of men and 96% of women caregivers reported having at

Table 10. Caregivers perceived support, available support and mean stress score by gender. (n = 409)

	Perceived Support %	Available Support %	Stress Score M
Men	91	64	9
Women	96	66	9

Figure 7
Proportion of caregivers providing assistance by type of activity.



Note: percentages do not total 100% due to multiple responses

least one person they can count on for support with their caregiving responsibilities (Table 10). Although nearly all said they have someone they could count on for support, only 64% and 66% of men and women respectively reported that they have someone who can relieve them on a regular basis from their caregiving duties (Table 10). While the perception of support among caregivers was fairly high, the proportion with available support for caregiving duties was 30% lower. The question remains why caregivers do not take advantage of other supports – is it because the nature and amount of assistance they provide is not great enough to warrant assistance from others? Are they uninformed about sources of support from outside the family, is it too costly? Do caregivers, particularly women, perceive this as their own responsibility and hesitate to involve others? Or does the person receiving assistance prefer family support, or even refuse support from “strangers”? The complex dynamics of help-seeking by caregivers are described and discussed by Gahagan et al. (2004) and further elucidated in ethnographic case studies by Beagan et al. (2005).

The majority of both men and women caregivers indicated that their spouse or common-law partner was the person they could count on for support (see Figure 7). Siblings were identified as another important support system, but to a lesser extent than spouses or common-law partners. Given that the majority of caregivers in this sample were providing care to an elderly parent, one might expect siblings to play an even larger role. One explanation might be that caregivers perceive this support as psychosocial support for themselves, not necessarily support for the person they provide care. Another explanation is that an individual’s spouse is typically the most available person in a caregivers’ support network given their proximity to the caregiver.

SUMMARY

Women in Nova Scotia made up the majority of caregivers (56%), although, a significant proportion of men (44%) were also involved in giving care to persons because of long-term health problem or temporary difficult time.

On average, the profile of men and women caregivers was similar in terms of their individual, living context, and socio-economic characteristics. It was only with care provision and characteristics related to support that the difference between men and women caregivers became apparent, and the reality of how caregivers, especially women, can become overwhelmed by caregiving responsibilities was demonstrated. Results from the 2005 Healthy Balance Survey indicated that women, who were more likely to participate in caregiving generally, were also more likely to provide assistance with ADLs/IADLs, activities requiring the most frequency in provision. Judging by the frequency in which these activities were provided, this suggests that women were more likely to be responsible for individuals with high care needs. This responsibility along with employment and family responsibilities may lead to a variety of social, psychological, physical, career, and financial consequences for women who provide care.

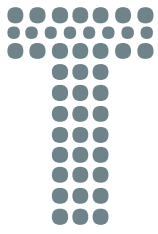
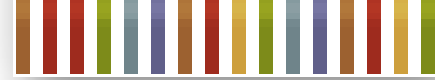
These consequences may be even greater in situations where caregivers have limited support from family, friends, and/or formal services. We learned in this study that almost all men and women caregivers felt that they had someone they can count on for support. However, only around two-thirds of both men and women reported receiving relief on a regular basis from caregiving duties from someone. Women caregivers were further disadvantaged, in that they are more likely to be widowed and therefore were less likely to have a spouse available as a primary source of support. Moreover since a greater proportion worked in part-time positions they would be



less likely to have access to support policies through their employment. It is with this in mind that policies must be developed and evaluated to ensure that they serve both women and men in an equitable manner

Nova Scotians Who Receive Care And Assistance

This study has demonstrated that Nova Scotians receiving assistance represent a very diverse group of individuals. Therefore this diversity must be considered in order to ensure that policy and programs are effective



his section focuses on Nova Scotians who received care/assistance⁷, attention, or errands from any organization or individual because of a long-term condition, mental illness or temporary difficult time or because they were ill, frail or disabled within the last 12 months. First, current knowledge about adults who receive assistance from others is provided. Next, a comparison of Nova Scotians who receive assistance in relation to the general Nova Scotia population is presented (weighted). Finally, a sample of 89 Nova Scotians who received assistance is analyzed by age to understand distinctive differences in the experience for those 19-54 years of age and 55 years of age and older. Gender differences among Nova Scotians who receive care will also be examined within this section.

CANADIAN OVERVIEW

The number of individuals with long or short-term health conditions who are able to receive the care they need within the home has grown over the last few decades due to a range of factors. Strategies to reduce the cost of services, such as deinstitutionalization, provision of acute care services within the home, advances in technology and pharmacology, along with increased life expectancy, and population aging has increased the number of individuals with short or long-term conditions in the community, who now often rely on formal support and/or assistance from family and friends (Evans et al., 2001; Fast, 2005).

In 2001 more than three million Canadians representing 12% of the Canadian population, were limited in their everyday activities due to a health related condition or problem (Statistics Canada, 2004). When this definition is broadened, the percentage receiving assistance is even higher. In fact, in 1996 the majority of Canadians (80% of non-seniors and 73% of seniors) living in the community reported receiving assistance with their everyday

activities. However, when looking at the reason behind needing assistance, only 3% of non-seniors and over 20% of Canadian seniors needed assistance because of a long-term health problem or physical limitation (Keating et al., 1999). In 2001, this senior population represented around 1 million Canadians (Cranswick, 2002).

Equally important in discussions of individuals receiving assistance is the younger population of adults with disabilities. It is estimated that approximately 3% of children (0-14 years of age) and 15% of adult (15 years of age and older) experience limitations in their everyday activities because of physical, psychological, or health conditions according to the 2001 Participation and Activity Limitation Survey (PALS) (Statistics Canada, 2004).

Individuals receiving care range in age, degree of acuteness, and reason for their condition. A greater proportion of seniors typically receive care because of a long-term health condition. Cranswick (2002) noted that 32% of senior women and 21% of senior men in Canada receive assistance because of a long-term health condition. Results from PALS indicate that adults with disabilities are more likely to be women, less educated, unemployed, and have low incomes (Statistics Canada, 2004). Furthermore, women receiving care who were age 65 and over were less likely to live with a spouse and more likely to live alone than men who received care (Cranswick, 2002).

Duration of need for assistance may vary across individuals receiving care, as their reasons for need differ. While some have long-term care needs due to aging or lifelong disabilities, others may have short-term care needs due to serious illness of themselves or family members. Changes in life expectancy, range of disabilities, and adequacy of formal services and support will play a role in changing care needs in the future.

7. Care and assistance will be used interchangeable throughout this section and refers to the non-financial assistance provided by caregivers.

Support Networks of Individuals Receiving Care

The support networks of individuals receiving care can be varied, including any combination of formal and family/friend support. Studies have shown that women typically have larger support networks, as women tend to be involved in more social interaction and mutual aid which facilitate closer relationships with friends and neighbours (Matud, Ibanez, Marrero, & Carballeira, 2003). Conversely, men receiving care may rely more on family members and other older neighbours within the community because they may not have large social networks or be willing to ask for help outside this network. This may balance out, in that men tend to marry younger women who are therefore likely to be available to provide care in times of need, whereas women are widowed at an earlier age and will have to rely on their larger support network for assistance. In addition, seniors with long-term health conditions are more likely to receive care from family and friends (39% of women, 46% of men), while care provision from formalized services is lower for women (25%) and men (24%) (Cranswick, 2002).

According to PALS, in 2001 63% of adults with disabilities who receive help obtain it from members of their family living with them, 42% from family members not living with them, 24% from friends or neighbours, and 14% from other sources.

Challenges to Individuals Receiving Care in the Home

Individuals receiving care face several challenges in meeting their care needs within their own homes and communities. First, the composition of the family is evolving. For instance, approximately one third of marriages result in divorce (Statistics Canada, 2004). The stress of this situation may be heightened,

especially when caregiving responsibilities are present. Research is lacking on how evolving family forms cope and what impact this has on individuals receiving care. These family forms may make it more difficult for family members to uphold caregiving responsibilities, which may result in a greater reliance on formal care services. Another family form that can affect individuals receiving care is the dual-earner couple which is increasing due to the need for both partners within the home to work and contribute to the household income. A study by Keefe and Medjuck (1997) found that economic factors impact on the degree of strain due to a lack of resources.

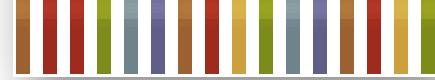
A second challenge for individuals receiving assistance with care, especially in rural areas, is the unavailability and inaccessibility of services within their communities. Efforts to deinstitutionalize people from hospitals and long-term care settings were not met with equal efforts to increase the availability of services within the community to support adults and seniors with care needs.

In order to understand what policies will benefit individuals receiving care who reside in their own home, one must first understand who these individuals are in terms of their socio-demographic and health profile and their care needs. By understanding the population that receives care, further work can be conducted to develop services, social programs, and policies that will strengthen an individual's ability to live independently within their community.

POPULATION-LEVEL PROFILE⁸

First a comparison between Nova Scotians who receive care and assistance to all adult Nova Scotians by individual characteristics, residency, and paid labour force participation are displayed in Tables 11, 12, and 13 respectively.⁹

8. Data for this section are based on respondents from Part I of the Healthy Balance Survey and the data are weighted to the population of Nova Scotia according to age, gender and rural/urban residency.



Individual Characteristics

In comparison to adult Nova Scotians in general, a greater proportion of individuals receiving care were older and in poorer health (Table 11). Almost 30% of Nova Scotians receiving assistance were 65 years of age and older, compared to only 16% of the adult Nova Scotian population. Around 40% of Nova Scotians receiving assistance reported their health as fair or poor, compared to only 15% of all Nova Scotians. A greater proportion of Nova Scotians who receive care compared to the general population reported higher levels of stress (27% compared to 22%). Although Nova Scotians receiving assistance may be challenged by higher care needs and lower health status,

Table 11. Individual characteristics, individuals receiving assistance and all Nova Scotians. (Adjusted weights; $n = 1988$)

	Individuals Receiving Assist. <i>n</i> = 179 %	All Nova Scotians <i>n</i> = 1988 %
Age		
19-44	34	48
45-64	36	36
65 +	29	16
Gender		
Women	55	52
Men	45	48
Perceived health status		
Excellent/very good	28	59
Good	31	27
Fair/Poor	41	15
Life satisfaction		
Very	37	48
Somewhat satisfied	44	42
Somewhat/very dissatisfied	19	10
Level of stress		
Not at all/not very stressful	38	34
A bit stressful	35	44
Quite a bit/extremely stressful	27	22

9. Chi-square analysis was not conducted as the populations are not independent of one another, i.e. individuals receiving assistance are included in the Nova Scotia population.

Table 12. Location of residence, individuals receiving assistance and all Nova Scotians. (Adjusted weights; $n = 1988$)

	Individuals Receiving Assist. $n = 179$ %	All Nova Scotians $n = 1988$ %
Urban	48	52
Rural	52	48

Table 13. Paid labour force participation, individuals receiving assistance and all Nova Scotians. (Adjusted weights; $n = 1988$)

	Individuals Receiving Assist. $n = 179$ %	All Nova Scotians $n = 1988$ %
Employment		
Not employed	67	45
Employed full-time	28	45
Employed part-time	5	10
Type of employment		
Permanent	63	72
Casual/Contract/ Seasonal/Other	20	17
Self-employed	17	11

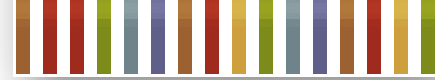
over 80% indicated being very or somewhat satisfied with life.

Residency

Among Nova Scotians who receive assistance there is little difference in the proportion who live in rural or urban communities compared to all Nova Scotians (Table 12). This finding is different than expected given the higher proportion of seniors in rural Nova Scotia and the resource based industry where disability and illness may be more prevalent. On the other hand, this expectation may be countered by the migration of individuals with disabilities to urban areas due to insufficient supports in the rural communities.

Paid Labour Force Participation

Table 13 illustrates that almost 70% of those receiving care and assistance were not employed, compared to 45% of the Nova Scotia population as a whole. This difference may be attributed to the higher, on average, age and poorer health status of Nova Scotians receiving care. However, individuals receiving care who were employed full-time represent 28% of the sample. Also, a greater proportion was self-employed compared to Nova Scotians in general. On a positive note this form of employment may be better suited to someone with health challenges, but it also means that they have less access to workplace benefits/policies which would help defray costs associated with their health conditions.



In summary, a greater proportion of individuals receiving care, when compared to the general adult population, was older, in poorer health, and experienced more stress. Over 30% of Nova Scotians receiving care were employed, mostly in full-time permanent positions, compared to almost 55% of all Nova Scotians. Individuals receiving care represent a diverse group, differing in age, limitations, reasons for needing assistance, and employment. One possible underlying reason explaining why individuals receiving care may differ is age. Therefore, we chose to conduct a comparison of Nova Scotians receiving care by age (19 to 54 years and 55 years and over). We believe that this comparison will prove most effective when addressing strategies to support Nova Scotians who receive care.

EXPLORING AGE DIFFERENCES AMONG INDIVIDUALS RECEIVING ASSISTANCE

The data for this section are based on a sub-sample of 89 Nova Scotians who receive assistance because of a long-term health condition or a health-related temporary difficult time and completed Part II of the Healthy Balance Survey.¹⁰ This section compares these individuals by age (19-54 and 55 and older) according to individual, living context, socio-economic status, and care provision characteristics.

Socio-demographic and Health Profile

Individual Characteristics

Although no significant age differences emerged, 47% of older adults (55 years of age and older) receiving assistance indicated

Table 14. Characteristics of individuals receiving assistance by age. ($n = 89$)

	19-54 $n = 46$ %	55 and over $n = 43$ %	Chi-Square χ^2
Gender			
Men	41	37	0.2
Women	59	63	
Perceived health status			
Excellent/very good	26	30	1.4
Good	35	23	
Fair/poor	39	47	
Life satisfaction			
Very satisfied	17	49	10.0**
Somewhat satisfied	61	37	
Somewhat/very dissatisfied	22	14	
Level of stress			
Not at all/not very stressful	18	40	5.5
A bit stressful	38	33	
Quite a bit/extremely stressful	44	28	

* $p < .05$, ** $p < .01$, *** $p < .001$.

10. Respondents who reported non-health-related temporary difficult times were excluded from analysis, this represented 13 Nova Scotians. This was done in an effort to provide a more homogeneous sub-sample of individuals receiving care.

their health status as fair/poor compared to 39% of younger adults (19 to 54 years of age) – individuals who perceived their health status of poor quality may have greater care needs (Table 14). Significant age differences occur in regards to life satisfaction. Data from the 2005 Healthy Balance Survey indicated that almost half of older adults were very satisfied with life, compared to only 17% of younger adults receiving care (Table 14). This difference in life satisfaction may be attributed to expectations of health at certain ages. For example, older adults receiving assistance may be more satisfied with their life because increasing health limitations are universally accepted as part of the aging process, so these individuals are more accepting of their reality because it is anticipatory. On the other hand, the need for care at a culturally inappropriate age may be a source of lower life satisfaction. Although chi-square analysis indicates no significant difference ($p = .06$), the prevalence of higher stress appears to be more dominant in younger

adults, opposed to older adults (Table 14). This finding is reasonable given that younger adults may have more demands placed on them in terms of employment, childcare, and household responsibilities. It also may be partially attributed to the fact that they are facing substantial barriers, stigma, and discrimination directed at them as persons with disabilities. Such stressors would, of course, increase their level of reported stress.

Living Context Characteristics

A similar proportion of both younger and older adults receiving assistance lived in urban areas (approximately 50%) and have lived in their community for at least four years (over 80%) (Table 15). Individuals receiving assistance differed by age group on marital status and living arrangement. Similar to findings in the larger Canadian population, older Nova Scotians receiving assistance were more likely to be widowed, 40% compared to 0% of younger

Table 15. Living context characteristics of individuals receiving assistance by age. ($n = 89$)

	19-54 <i>n</i> = 46 %	55 and over <i>n</i> = 43 %	Chi-Square χ^2
Residency			
Urban	50	51	0.0
Rural	50	49	
Marital status			
Married/common-law	57	37	22.6***
Divorced/separated	22	12	
Widowed	0	40	
Never married/single	22	12	
Living arrangement			
Living alone	22	55	10.2**
Living with others	78	45	
Length in community			
0 - 3 yrs	20	9	1.8
4 + yrs	80	91	

* $p < .05$, ** $p < .01$, *** $p < .001$.



Table 16. Socio-economic characteristics of individuals receiving assistance by age. ($n = 89$)

	19-54 $n = 46$ %	55 and over $n = 43$ %	Chi-Square χ^2
Education level			
High School diploma or less	20	44	6.6
Some college or university	24	19	
Diploma/certificate	26	14	
At least post-secondary	30	23	
Employment			
Not employed	46	98	-- ^a
Employed full-time	46	2	
Employed part-time	8	0	
Household gross income			
\$0-\$19,999	17	30	3.1
\$20,000-\$39,999	31	26	
\$40,000-\$59,999	19	26	
\$60,000 +	33	17	

^aNo chi-square because of cell violations.

* $p < .05$, ** $p < .01$, *** $p < .001$.

adults in this study and they were more likely to live alone than their younger adult counterparts. This has implications in terms of the support network for individuals receiving assistance. Older adults may be more vulnerable, since they are less likely to be married, less likely to have live-in support, their support networks are likely smaller, and they will have to rely on children, siblings, friends, or formal services. The literature suggests that this network is often limited in terms of its availability and its assistance with tasks.

Socio-economic Status

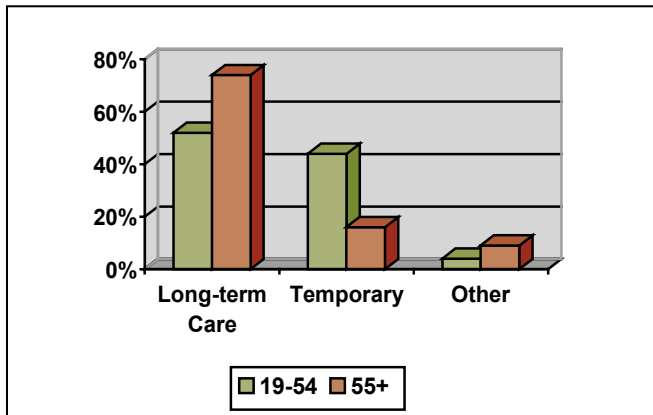
There were some similarities and differences in the socio-economic characteristics defining younger and older adults receiving assistance. While chi-square analysis indicates no significant difference, a greater proportion of older adults receiving assistance reported their highest level of education as high school or less (44%) compared to younger adults receiving

assistance (20%) (Table 16). Lower education has implications on income which can affect resource availability and indirectly may affect the health status of the individual.

Very few older adults were employed full-time at the time of the survey, only 2%, compared to 46% of younger adults (Table 16). This finding speaks to larger employment trends, where those 55 years of age and older are more likely to be retired. Plus, given that this population depicts those receiving care, increases in care needs as one ages decreases the likelihood of employment. The high proportion of younger adults who were employed may place them at an advantage as they may have access to workplace benefits and support policies. However, they may also be at more risk for stress and burden as they are balancing their own care needs with employment and family responsibilities (Table 16).

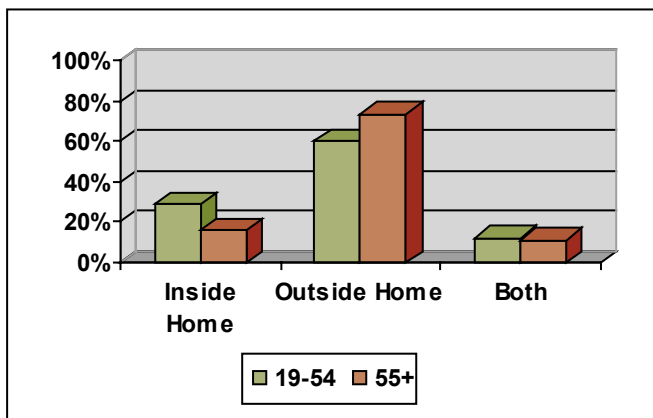
As shown in Table 16, there was no significant

Figure 8
Proportion of individuals receiving assistance by reason.



Note: percentages do not total 100% due to multiple responses

Figure 9
Proportion of individuals receiving assistance from caregivers who live inside and/or outside their home.



difference in household income between younger and older adults receiving assistance. In general, the incomes of persons with disabilities in Nova Scotia are significantly lower than those in the general population and particularly are so among working-aged women with disabilities, where the unemployment rate is highest (Nova Scotia Advisory Council on the Status of Women, 2004).

Care Provision

Not only did younger and older adults receiving assistance differ according to their socio-demographic and health profile, but they also differed in terms of who they received assistance from, what activities they received assistance with, and why they needed assistance. For example, the majority of both younger and older adults received assistance because of a long-term health problem; however a much larger proportion of younger adults received assistance due to health-related temporary difficult times than older adults (Figure 8). This suggests that older adults may require care for prolonged periods of time in order to live independently. As for younger adults receiving assistance, they may need acute care, but for shorter durations, which impacts on the type of care that is needed and who provides the care.

A slightly greater proportion of younger adults received assistance from someone who lived within their home only, but the majority of both younger and older adults received assistance from a non-reside caregiver (Figure 9). This is consistent with previous findings that younger adults were more likely to be married and living with others.

Older adults, who potentially have a smaller network, may rely more on people who live outside their house for assistance. With this in mind, the relationship of individuals receiving assistance to their source of support was examined. Chi-square results indicate no significant difference between age groups



(Figure 10). In a separate analysis, results show that older adults were more likely to receive assistance from home care agencies (33% of older adults compared to only 7% of younger adults).

According to the literature, the relationship of the individual receiving assistance to the provider may affect the types of activities received. Care tasks were grouped into 6 activities: ADLs/IADLs, psycho-social support, facilitation/supervision, orchestrating care, transportation/shopping, and house maintenance (see Table 8). Younger and older adults differed significantly on two types of activities: orchestrating care and transportation/shopping. A greater proportion of younger adults received assistance with orchestrating care (35%), while conversely, a greater proportion of older adults received assistance with transportation and shopping (75%) (Figure 11). In general, assistance with transportation/shopping, psycho-social support and ADLs/IADLs were the highest reported activities with which both younger and older adults received assistance.

Figure 10

Proportion of individuals receiving care by their sources of support.

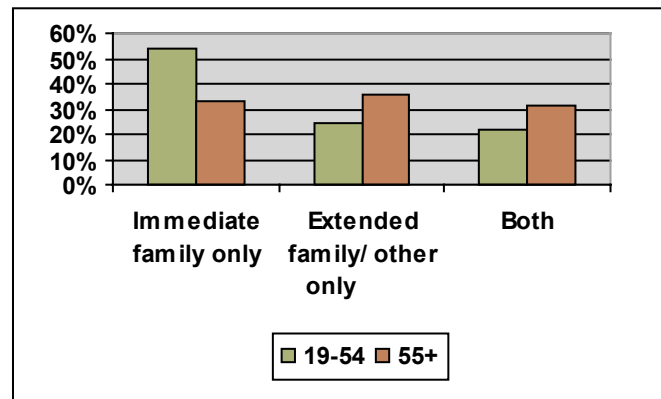
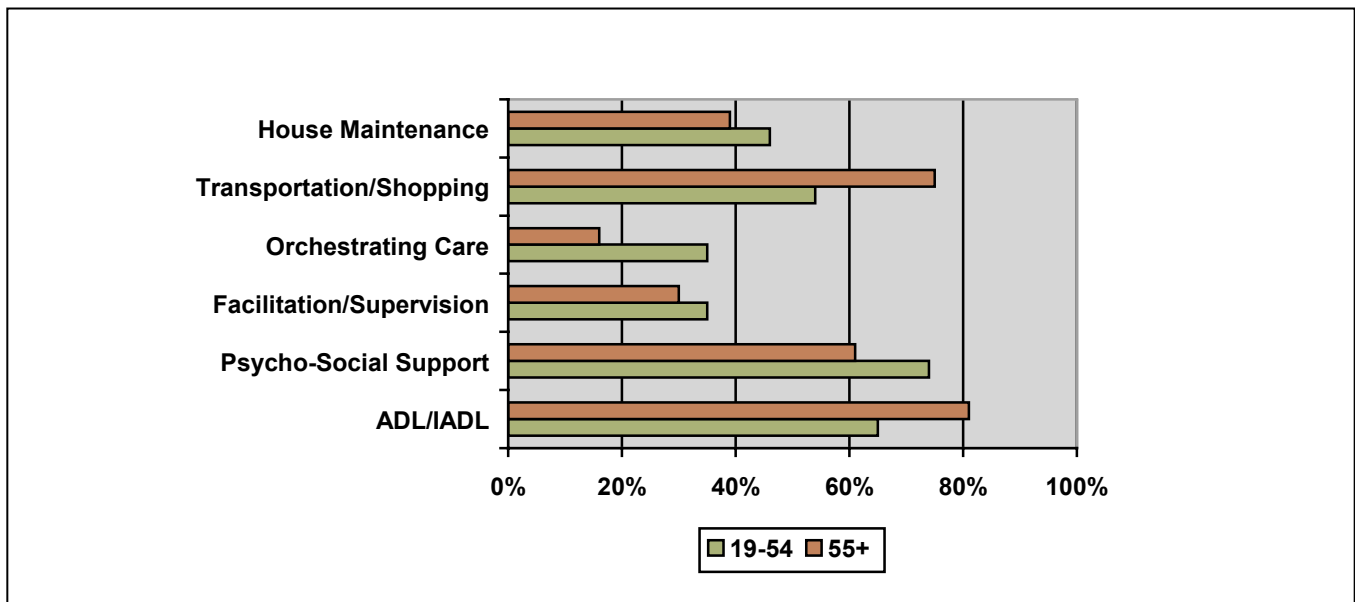


Figure 11

Proportion of younger and older Nova Scotians receiving assistance by type of activity.



Note: percentages do not total 100% due to multiple responses

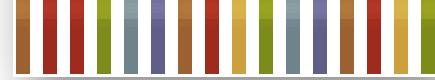
To understand the extent of care received the number of activities and the frequency with which they were provided were calculated. The results show that for both younger and older adults, receiving assistance with ADLs/IADLs and psycho-social support required the greatest frequency compared to other activities (Table

Table 17. Frequency of activities provided to individuals receiving assistance by age. (n = 89)¹¹

	19-54 n = 46 %	55 and over n = 43 %	Chi-Square χ^2
Total tasks			
Less than weekly	25	24	1.6
Weekly-daily	15	26	
More than daily	60	50	
ADL/IADL			
None	25	17	1.1
Less than weekly	18	24	
Weekly-more than daily	58	59	
Psycho-social support			
None	15	38	5.7
Less than weekly	28	17	
Weekly-more than daily	58	45	
Facilitation/supervision			
None	60	69	.7
Less than weekly	20	14	
Weekly-more than daily	20	17	
Orchestrating care			
None	60	83	6.3*
Less than weekly	20	12	
Weekly-more than daily	20	5	
House maint./outdoor work			
None	48	60	1.3
Less than weekly	38	31	
Weekly-m ore than daily	15	10	
Transportation			
None	38	24	1.8
Less than weekly	35	43	
Weekly-more than daily	28	33	

*p < .05, **p < .01, ***p < .001.

11. These data are not standardized and are based on factors identified in factor analysis. The frequency of activity provision is in part resulting from the number of tasks included within each activity.



17). The only activity in which frequency differed among younger and older adults was in the task area of orchestrating care, in that younger adults received this assistance more often than older adults.

EXPLORING GENDER DIFFERENCES AMONG INDIVIDUALS RECEIVING ASSISTANCE

In addition to understanding how individuals in Nova Scotia may differ according to age, we examined whether gender contributes to the differential experiences of those receiving care in Nova Scotia.

Socio-demographic and Health Profile

In this study, men and women in Nova Scotia who receive assistance with care do not appear to differ significantly in terms of their socio-demographic and health characteristics. A

greater proportion of both men and women receiving assistance were 65 years of age and under and perceived their health status as being lower (Table 18). Despite reporting a lower health status, both men and women, for the most part, were somewhat or very satisfied with life and had low levels of stress.

The majority of men (67%) and women (59%) lived with others, however, a much greater proportion of men than women were married or living common-law (61% versus 37% respectively). Alternatively, women were more likely to be widowed than men (28% versus 6% respectively) (Table 19). Men can then rely on their spouse for care provision, while women do not have the same benefit.

Results show that education, employment, and household incomes of men and women who receive assistance in Nova Scotia did not differ

Table 18. Characteristics of individuals receiving assistance by gender. (*n* = 90)

	Men <i>n</i> = 36 %	Women <i>n</i> = 54 %	Chi-Square χ^2
Age			
19-44	29	33	1.9
45-64	46	32	
65 +	26	35	
Perceived health status			
Excellent/very good	22	32	.96
Good	33	28	
Fair/poor	44	41	
Life satisfaction			
Very satisfied	36	30	.79
Somewhat satisfied	50	50	
Somewhat/very dissatisfied	14	20	
Level of stress			
Not at all/not very stressful	43	20	5.4
A bit stressful	26	41	
Quite a bit/extremely stressful	31	39	

p* < .05, *p* < .01, ****p* < .001.

Table 19. Living context characteristics of individuals receiving assistance by gender.¹²
(*n* = 90)

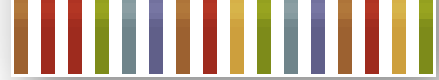
	Men <i>n</i> = 36 %	Women <i>n</i> = 54 %	Chi-Square χ^2
Marital status			
Married/common-law	61	37	9.1*
Divorced/separated	19	15	
Widowed	6	28	
Never married/single	14	20	
Living arrangement			
Living alone	33	42	.6
Living with others	67	59	
Length in community			
0 - 3 yrs	17	13	.3
4 + yrs	83	87	

**p* < .05.

Table 20. Socio-economic characteristics of individuals receiving assistance by gender.
(*n* = 90)

	Men <i>n</i> = 36 %	Women <i>n</i> = 54 %	Chi-Square χ^2
Education level			
High School diploma or less	29	33	1.1
Some college or university	20	22	
Diploma/certificate	26	17	
At least post-secondary	26	28	
Employment			
Not employed	58	69	.98
Employed	42	32	
Household gross income			
\$0-\$19,999	17	28	7.6
\$20,000-\$39,999	20	36	
\$40,000-\$59,999	20	22	
\$60,000 +	43	14	

12. Residency was not included in this analysis, as findings would be a direct result of stratification techniques using gender and rural/urban residency.



significantly in some cases a function of the smaller sample size in this subsample (Table 20). For example, more men than women were employed, 42% and 32% respectively, although the difference was not statistically significant. Noting that women's employment generally is more likely to be part-time and in service sector industries, there may be gender differences in access to supportive workplace policies that are unable to be captured in this study.

Care Provision

Finally, differences in the experience between men and women who receive care were examined. Results suggest that men and women did not differ in the type and amount of care they receive, the reason why they receive care, or who provides the care. This finding is different than expected and further analysis is needed to better understand important contextual variables such as age and income.

SUMMARY

Findings from 2005 Healthy Balance Survey reveal that Nova Scotians who receive assistance, in comparison to the general Nova Scotia population, are older and mostly not employed. They perceive their health to be poorer and are more likely to experience higher levels of stress. These findings have implications

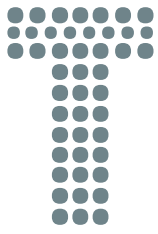
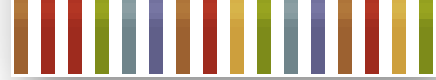
for their well-being and that of their families.

For the most part, age grouping and gender were not related to care provision characteristics. Results show that younger adults receiving care reported being less satisfied with life, more likely to be married or living common-law, living with others and in terms of care provision, a greater proportion reported receiving assistance with orchestrating care, and a smaller proportion receiving assistance with transportation and shopping. It appears from the data in this study that gender is not a useful characteristic in understanding care recipients. The marital status of men and women does differ; however, this gender difference transcends different populations. However, this finding does have implications, especially for women, because it means that they are more likely to be further disadvantaged, as their support network may be smaller and household income lower, preventing them from accessing resources.

While such heterogeneity as well as the small sample size may result in few conclusive findings about these individuals, the recognition of such heterogeneity is important when considering strategies to support these individuals and their care providers. Policy makers should be mindful that one approach may not be suitable for all.

Issues For Policy Consideration

The prevalence of caregiving is higher in Nova Scotia than in Canada and points to essential support that family and friends make to the lives of many Nova Scotia residents. This finding is important because it places the need for adequate caregiver support high on the policy agenda. Intergovernmental arrangements, particularly those related to financing of health and caregiving initiatives, must take this higher prevalence of caregiving into account.



The information gathered by the Healthy Balance Survey provides a valuable profile of unpaid care in Nova Scotia. These baseline data are essential to understanding provincial characteristics and will serve as a benchmark for other research in this area. While a full discussion of the policy implications of the survey caregiving has to await the completion of subsequent reports in the series, several findings of this report are of great importance. Highlighted below are the key findings of the survey and a brief discussion of the issues that have implications for policy consideration.

More than one-third of the Nova Scotia population identifies as a ‘caregiver’ meaning that they are providing care for an individual due to a long-term condition, mental illness or temporary difficult time.

The prevalence of caregiving is higher in Nova Scotia than in Canada and points to essential support that family and friends make to the lives of many Nova Scotia residents. This higher prevalence reinforces that this is an important area where resources and policy needs to be directed in order to support Nova Scotians in their caregiver role. The survey findings are further supported by the work of Lethbridge and colleagues (2005) who found that women in Atlantic Canada as a whole spend much more time caregiving than other Canadians. This finding is important because it places the need for adequate caregiver support high on the policy agenda. Intergovernmental arrangements, particularly those related to financing of health and caregiving initiatives, must take this higher prevalence of caregiving into account.

Policy must reflect the diversity of caregiving situations. Whether individuals are relying on unpaid care because of a lack of formal

services or because of choice, policies should be developed to support unpaid caregiving. The challenge of trying to address the situation with one program or service is insurmountable. The practice of caregiver assessment is of crucial importance to understand their specific needs and best ways to support them. Flexibility and choice need to be embraced in policy discussions. In all cases the policies must reflect the diversity of caregivers and individuals who receive care within the Nova Scotia context and as such its implications reviewed through a gender, diversity and rural lens.

Nova Scotians receiving care are “aging in place” and do not co-reside with their caregiver.

Almost 80% of Nova Scotia caregivers do not reside with the person for whom they provide care; although the majority live within a short distance. People who need assistance are choosing to age in place, living within their own homes for as long as possible, thereby delaying institutional care. This is consistent with current deinstitutionalization policies supported by the government.

Policy development can benefit from this knowledge of the physical location of caregivers in Nova Scotia. Policy that supports unpaid caregiving will need to address issues related to providing care for individuals living in their own homes, and for caregivers who travel short and long-distances. The distances to provide care, for the majority of caregivers who do not live with the care recipient is especially problematic, when considering the number of rural communities in Nova Scotia and the number of young persons who are migrating from their home towns to the city for employment. These migration patterns reduce the potential supply of available support in rural areas in the short-term and in the future. In this case policies need to be both reactive and proactive. Recognition of the “caregiver at a distance” model calls for initiatives that

support community programs and formal services, and build on potential support networks of individuals in need of assistance. Formal supports might include additional services, including expanding on independent and assistive living options. Finally, proactive policies to enable rural residents to earn a living without leaving their area will facilitate the availability of caregivers in the future.

A significant proportion of caregivers are baby boomers.

Currently, baby boomers represent a significant proportion of the population and because they are middle aged, their likelihood of having elderly parents is very high. The highest proportion of Nova Scotia caregivers were in this middle aged group. Policy designed to support caregivers must be able to recognize the ways in which the additional responsibilities of caregivers affect and intersect with their caregiving. For example, caregivers in the baby boomer generation are likely to be combining caregiving with employment and childcare responsibilities. Some formal care policies are built on the assumption of caregiver availability; given the multiple roles/responsibilities of these caregivers the assumption becomes more problematic. It is believed that the baby boomer generation will not only need more support, but will also be more vocal than previous generations in demanding services that meet their individual needs.

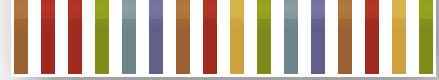
Policy needs to be able to accommodate the various needs of different generations of caregivers. Flexibility and choice will be key to any support initiatives. Such initiatives should also encompass an understanding of changing definitions of family, the realities of combining different types of care, and changing perceptions of individual roles and responsibilities.

Caregivers feel high levels of stress.

As individuals take on multiple roles, especially the role of caregiver, their stress levels may increase. Stress may be the result of trying to balance multiple roles, unfamiliarity with caregiving, burden and overload, and problems in the caregiver-receiver relationship. Increased levels of stress can negatively impact the health of the caregiver and may lead to the breakdown of the caregiving relationship. Increased levels of stress may also affect the caregiver's employment, and other responsibilities and relationships.

Women and men have different experiences of caregiving. The caregiving tasks performed by women and men are different and therefore, their caregiving roles have different impacts on their lives.

The provision of care is still very much rooted in gender roles in today's society. Women are still primarily involved in the provision of care in the home whereas men are primarily involved in assisting with activities outside the home. Care within the home tends to be more intensive and requires greater time commitments. Policy developed to support caregivers must apply a gender lens in order to ensure that policies and programs support the different needs of women and men and take into account women's and men's differing access to resources. In doing so, policy must acknowledge the primary role of women in unpaid caregiving without entrenching caregiving as 'women's work'. Assessment of caregiver support needs will be of crucial importance so that those caregivers who most need support receive it.



Caregivers just as likely to be in labour force as non-caregivers, but women more likely than men to be employed part-time.

While women caregivers are just as likely to be employed as men caregivers, their employment is more likely to be part-time. Whether part-time status was a result of caregiving responsibilities is unknown, but other research has demonstrated that women are more likely to experience employment costs because of caregiving. Such costs include reduced incomes, reduced hours of work, reduced savings, passing up promotions, training, etc.

Part-time employees, unlike full-time employees are less likely to have access to work place policies that may be supportive of caregiving responsibilities. One perceived benefit associated with part-time employment is flexibility. This flexibility may be a misconception however, as part-time workers may be working part-time at more than one job and accumulate full-time hours with neither the full-time benefits nor the flexibility to provide care. The fact that about half of the caregivers in Nova Scotia are also employed for pay has implications for the type of supports they may need, for example, flexible schedules, employment paid leave, pension protection, and so on.

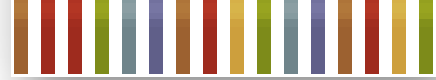
Nova Scotians receiving assistance are not a homogenous group.

Nova Scotians receiving assistance range in age, socio-economic status, and care needs. The implications for policy are vast and far-reaching depending on the type of assistance needed and duration of care. Those needing assistance because of long-term health problems, will probably differ from those who need assistance because of temporary difficult times. Age is another factor that is important to consider for the policy implications of individuals receiving

assistance. Most of those under age 55 are married, receive assistance from someone in their household, and many are employed. Those aged 55 and older were living alone and receive assistance from others outside their household. Their needs may more closely represent the continuum of care model where they can move into increasingly supportive housing (in terms of the range of services).

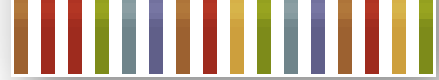
This study has demonstrated that Nova Scotians receiving assistance represent a very diverse group of individuals. Therefore this diversity must be considered in order to ensure that policy and programs are effective. One approach to addressing the diversity is to create policies that are flexible, and to offer several policies options so Nova Scotians receiving assistance can choose support policies which best suit their caregiving situation.

References



- Beagan, B., Stadnyk, R., Loppie, C., MacDonald, N., Hamilton-Hinch, B., & MacDonald, J. (2005). *"I do it because I love her and I care": Snapshots of the lives of caregivers*. Halifax, NS: Atlantic Centre of Excellence for Women's Health.
- Chappell, N.L. (1992). *Social support and aging*. Toronto: Butterworths.
- Cranswick, K. (2002). *General Social Survey Cycle 16: Caring for an aging society*. Statistics Canada. Catalogue no. 89-582-XIE
- De Peuter, J. & Sorensen, M. (2005). *Rural Nova Scotia profile: A ten-year Census analysis (1991-2001)*. Report prepared for Rural Secretariat, Ottawa. Catalogue no. A114-13/8-2001E-PDF
- Evans, R.G., McGrail, K.M., Morgan, S.G., Barer, M.L. & Hertzman, C. (2001). Apocalypse now: Population aging and the future of health care systems. *Canadian Journal on Aging*, 20(1), 160-191.
- Fast, J. (2005). Caregiving: A fact of life. *Transitions*, Summer 2005. The Vanier Institute of the Family.
- Gahagan, J., Loppie, C., MacLellan, M., Rehman, L., & Side, K. (2004). *Caregiver resilience and the quest for balance: A report on findings from focus groups*. Halifax, NS: Atlantic Centre of Excellence for Women's Health.
- Guberman, N. & Maheu, P. (1999). Combining employment and caregiving: An intricate juggling act. *Canadian Journal on Aging*, 18(1), 84-106.
- Hayward, K., & Colman, R. (2003). *The tides of change: Addressing inequity and chronic disease in Atlantic Canada. A Discussion Paper*. Prepared for Population and Public Health Branch, Atlantic Regional Office, Health Canada.
- Hébert, R., Dubuc, N., Buteau, M., Desrosiers, J., Bravo, G., Trottier, L., St-Hillaire, C., & Roy, C. (2001). Resources and costs associated with disabilities of elderly people living at home and in institutions. *Canadian Journal of Aging*, 20(1), 1-21.
- Joseph, A. & Hallman, B. (1996). Caught in the Triangle: The influence of home, work, and elder location on work-family balance. *Canadian Journal on Aging* 15(3), 393-412.
- Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content and consequences*. Statistics Canada. Catalogue no. 89-570-XPE
- Keating, N., Kerr, K., Warren, S., Grace, M., & Wertenberger, D. (1994). Who's the family in family caregiving. *Canadian Journal on Aging*, 13(2) 268-286.
- Keefe, J., Légaré, J., & Carrière, Y. (2005). Developing new strategies to support future caregivers of the aged in Canada: Projections of need and their policy implications. *Social and Economic Dimensions of an Aging Population* (SEDAP: Research Papers Series).
- Keefe, J.M., & Medjuck, S. (1997). The contribution of long term economic costs to predicting strain among employed women caregivers. *Journal of Women & Aging*, 9(3), 3-25.
- Keefe, J.M., & Side, K. (2003). *Net loss population settlement patterns and maintenance of rural health status: A case study in Atlantic Canada*. Final Report. Halifax, NS: Mount Saint Vincent University.
- Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist*, 35(3), 340-348.
- Lafreniere, S., Carriere, Y., Martel, L., & Belanger, A. (2003). Dependent seniors at home- formal and informal help. *Health Reports*, 14(4), 31-40.
- Lethbridge, L., MacDonald, M., & Phipps, S. (2005) Taking its toll: Implications of paid and unpaid work responsibilities for women's well-being. *Feminist Economics*, 11(1), 65-96.
- MacDonald, M., Phipps, S., & Lethbridge, L. (2005). Total packages of work: Women living in Atlantic Canada compared to the rest of Canada. *Atlantis*, 30(1), 105-121.
- Matud, M.P., Ibanez, I., Marrero, R., & Carballeira, M. (2003). Structural gender differences in perceived social support. *Personality and Individual Differences*, 35(8), 1919-1929.
- Nova Scotia Advisory Council on the Status of Women. (2004). *Women and economic autonomy in Nova Scotia*. Facts and Figures.
- Roehrer Institute. (2003). *Caregivers of persons with disabilities in Canada and policy implications*. Unpublished paper prepared for Canadian Association for Community Living.
- Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10, 277-286.
- Statistics Canada. (2002). *A national overview: Population and dwelling counts, 2001 Census*. Ottawa: Author. Catalogue No. 93-360-XPB
- Statistics Canada. (2004). Profile of disability in 2001. *Canadian Social Trends*. Ottawa: Author. Catalogue no. 11-008

Appendices



APPENDIX A

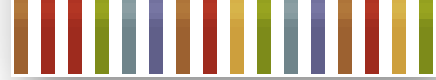
Healthy Balance Research Program

The Healthy Balance Research Program (HBRP) is funded by the Canadian Institutes of Health Research (CIHR). This community-researcher alliance program is under the direction of the Atlantic Centre of Excellence for Women's Health located at Dalhousie University, the Nova Scotia Advisory Council on the Status of Women, Province of Nova Scotia, and the Women's Health Research Unit of the Institute of Population Health at the University of Ottawa.

The HBRP is a collaborative community-based research program comprised of academic researchers, stakeholder organizations, and community members. The organizational structure consists of four research teams, three co-directors, trainees (postdoctoral fellow and graduate students) and support staff. The program is managed by the three co-directors

and the program coordinator. At the heart of Healthy Balance is the Equity Reference Groups. These advisory groups consist of members of the four targeted groups of Healthy Balance: African-Nova Scotian women, women with disabilities, immigrant women, and Aboriginal women.

The four research teams investigated caregiving from diverse methodological perspectives and conducted research on the impact of caregiving on women's well-being. One team examined existing secondary data to better understand the time involved in caregiving and the associated impacts on women's lives. Using a qualitative methodological approach, a second team conducted 18 focus groups on women's unpaid caregiving across a wide variety of situations. The Caregiver Portrait's team created 14 ethnographical portraits on the caregiving relationships of two women from each Equity Reference Group. This monograph is the first report of a fourth group - the population-based survey team.



APPENDIX B- RESEARCH DESIGN

Telephone Survey

Members of the HBRP Phase II Team developed the HBRP Phase II Telephone Survey during 2003-04 with input from key stakeholders, particularly the Equity Reference Groups, described above (Appendix A). The survey is comprised of mostly close-ended questions. In addition to original questions developed by the research team, it includes select questions from national surveys (e.g., General Social Survey, Census) and validated scales¹³.

The survey has two parts. Part 1 contains 15 questions and was asked of all respondents to gather information on basic demographic characteristics (employment, gender, age, rural/urban residency, ethnicity, health, stress, life satisfaction, unpaid work) of Nova Scotians. Part 2 was asked only of caregivers or care recipients, and contains detailed questions on household composition, caregiving relations, physical and mental health, employment, resiliency and stress, and demographics.

Sampling

The University of Alberta's Population Research Laboratory administered the survey between February and May 2005. Almost 10,000 Nova Scotia households were contacted using a random digit dialing approach. The target population for the survey was English speaking Nova Scotians 19 years of age or older.

The sample in Part I consisted of 1,988 English-speaking Nova Scotians 19 years of age and older. Only those individuals who indicated they gave and/or received care in Part I were invited to participate in Part II. The sample for Part II was also stratified on the basis of give/receive care, rural/urban residency, and male/female. To ensure equal representation by gender and to strengthen comparative analysis, males were over sampled. Part II was completed by 465

respondents. The response rate for Part I was 42% and for Part II was 74%. The difference in response rates between Part I and Part II suggests that those who were eligible were interested in continuing with the survey. Of Nova Scotians who gave care and who were eligible and could continue on to complete survey, 74% did so. On the other hand, only 38% Nova Scotians who received care and were eligible and could continue on to complete the survey did. A Computer Assisted Telephone Interviewing System (CATI) was used to conduct the survey and track responses. On average Part I took 7 minutes to complete, and Part II was completed in 23 minutes.

Analysis

Data were analyzed using the Statistical Package for the Social Sciences, (v.13) (SPSS). Estimates produced from Part I data were calculated by using weights for age, gender, and rural/urban residency (based on 2001 Census results). The results of various univariate (frequencies) and bivariate analyses (chi-square test) by caregiver/non-caregiver, men/women, and age groups are presented to gain a deeper understanding of unpaid care in Nova Scotia.

For presentation purposes, descriptive characteristics are grouped as follows:

Individual characteristics – refers to demographic characteristics such as sex, age, perceived health status, life satisfaction, and stress.

Living context – refers to characteristics that measure household context in terms of available social support such as rural/urban residency, marital status, living arrangement, and length in community.

Socio-economic status – refers to characteristics that are indicators of social status and resource availability, including employment, education, and household income.

13. Copies of the Healthy Balance Survey questionnaire are available upon request.

Care provision – refers to the attributes that define the care relationship such as activities, reason for care, and information on the person receiving or providing care.

Definitions key to understanding sample populations are outlined in Table 1.

Table B displays a comparison of the Healthy Balance Survey data to Nova Scotia 2001 Census data according to key demographic variables. Results in this table indicate that the Healthy Balance data are mostly representative of the Nova Scotia adult population according to age, gender, rural/urban residency, and ethnic group, with the exception of those identifying Canadian as a single origin. This discrepancy on “Canadian” may have resulted due to the nature of the Census survey (written) compared to the Healthy Balance survey (telephone). Participants may have been more likely to check off multiple responses since the options were

all outlined on the questionnaire. In 2005, just over half of the Nova Scotia population were female, lived in urban areas, and self-identified their ethnicity as just Canadian (see Table 2). Almost 20% of adult Nova Scotians were 65 years of age and older.

Regional Comparisons of Unpaid Work

In 1996 and 2001, the Canadian Census included questions on unpaid work in an effort to capture information on the prevalence and amount of assistance Canadians give to others. The same questions were included in the 2005 Healthy Balance Survey. The provision of unpaid work (household and childcare) in Nova Scotia, Atlantic Canada, and Canada was compared using data from the 2005 Healthy Balance Survey and the 2001 Census. These data on unpaid work provide insight into the patterns and prevalence of caregiving in Nova Scotia.

Table B-1. Definitions.

Caregiver: person who provided care, attention, or errands for any individuals who have a long-term condition, mental illness or temporary difficult time or who is ill, frail or disabled within the last 12 months.

Individuals receiving care/assistance: person who received care, attention, or errands from any organization or anyone because of a long-term condition, mental illness or temporary difficult time or because they were ill, frail or disabled within the last 12 months.

Long-term health problem: a condition(s) that has lasted or is expected to last 6 months or more and which can be either chronic or permanent.

Temporary difficult time: a condition(s) that is not expected to last more than 6 months. Causes of temporary difficult time may include: financial problems; unemployment; birth of child/pregnancy/adoption; problems with children; separation/divorce; short-term illness or minor injury of self, spouse/partner, or family member; serious injury of self, spouse/partner, family member or friend; death of spouse/partner or close friend; or other.

Rural/urban residency: Nova Scotians within the Halifax Regional Municipality or Cape Breton County were designated as having urban residency; Nova Scotians from other areas were designated as having rural residency.

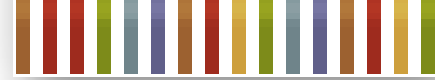


Table B-2. Comparison of adult Nova Scotians from the Healthy Balance Survey and the 2001 Census according to age, gender, ethnic group and residency.

	HB Survey <i>n</i> = 1988 ^a %	2001 Census <i>n</i> = 683,669 %
Age		
19-44	48	49
45-64	36	34
65-74	9	10
75-84	6	6
85 +	1	2
Gender		
Female	52	52
Male	48	48
Ethnic group (single origins)		
African	.8	.4
British	12	19
French	7	3
Aboriginal	2	.9
Canadian	50 ^b	27
Residency^c		
Urban	52	52
Rural	48	48

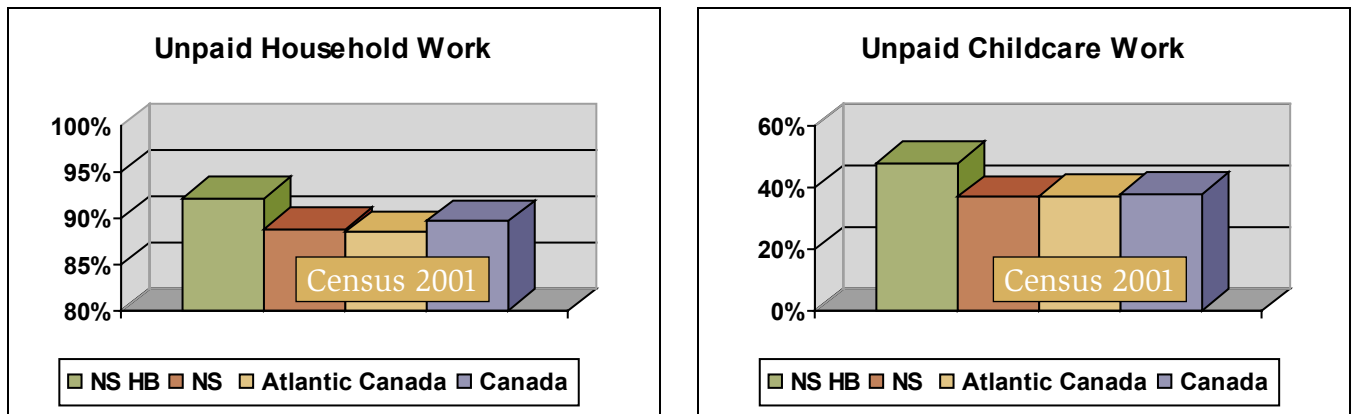
^aAdjusted weights (*n* = 1988).

^bThis may be higher than the Census reports because the survey was conducted only in English; as a telephone survey, the respondent did not see the many categories as is in the case of the Census long survey form and may have been less likely to chose multiple ethnicities.

^c2001 Census data for residency are based on Nova Scotians of all ages.

Figure B-1

Regional comparisons of the proportion participating in unpaid household and childcare work.



Census data for Nova Scotia, Atlantic Canada, and Canada (Figure 1) do not show substantial differences. In comparison, a slightly greater proportion of Nova Scotians in the Healthy Balance Survey reported providing assistance with unpaid household work, 92% compared to 89% in the Census. Similarly, the Healthy Balance Survey shows 48% of Nova Scotians providing unpaid childcare compared to 37% in the Census. These results may be a function of different data collection methodologies

and the four year difference between survey administration. Regardless, Nova Scotians compared to other Canadians generally engaged in similar if not more unpaid assistance to others. Furthermore, based on data from the 1998 General Social Survey, Lethbridge, MacDonald, and Phipps, (2005) noted that a greater proportion of women in Atlantic Canada reported providing eldercare (30%) than Canadian women overall (26%).

A Portrait of Unpaid Care in Nova Scotia documents the extent of caregiving by Nova Scotians, the impacts of caregiving, and discusses the implications of these findings for policy makers.

Family and friends provide the majority of care and assistance that individuals with health limitations receive. This care is typically unpaid and provided mostly by women. Today, these realities are challenged by the current socio-demographic context which includes population aging, deinstitutionalization, high labour force participation of women, and migration patterns. These factors suggest an increasing demand for care, yet question the availability and capacity of family and friends as caregivers

Policy must reflect the diversity of care situations in Nova Scotia by recognizing the importance of flexibility and choice in service options. Assessing caregivers and individuals who receive care is key to understanding their specific needs and the best way to support them.

HBRP | Healthy Balance
Research Program

The Healthy Balance Research Program is funded by the Canadian Institutes of Health Research and is supported by Dalhousie University, IWK Health Centre and the Women's Health Bureau, Health Canada.

PO Box 745

Halifax, Nova Scotia

B3J 2T3 Canada

Tel: 902-424-7630

Fax: 902-424-0573

www.healthyb.dal.ca