EXAMINING CHANGES IN CAREGIVING DURING AND AFTER THE ATLANTIC GROUNDFISH STRATEGY IN A SELECT NEWFOUNDLAND COASTAL COMMUNITY AFFECTED BY THE COD MORATORIUM

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Examining Changes in Caregiving During and After The Atlantic Groundfish Strategy in a Select Newfoundland Coastal Community Affected by the Cod Moratorium

by

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Abstract

Examining Changes in Caregiving During and after The Atlantic Groundfish Strategy in a Select Newfoundland Coastal Community Affected by the Cod Moratorium

The purpose of this study was to compare informal caregivers in a coastal Newfoundland community during the fishery closure at two time periods: a) when The Atlantic Groundfish Strategy (TAGS), a federal government program that provided financial support for those affected was in place (phase 1) and b) after TAGS completion (phase 2). **Method:** This study involved secondary analysis of data collected during two time periods. The data were collected in the same geographic area at both times, using a randomly selected sample. The first set of data was collected in 1995-1997, during the first study, an interdisciplinary Eco-Research program entitled *Sustainability in a Changing Cold-Ocean Coastal Environment,* while individuals who were affected by the cod moratorium were receiving income support through TAGS. The second set of data was collected in 2001-2003, during the *Natural Resources Depletion and Health* study which was conducted after the TAGS program had been completed. The sample consisted of individuals who identified themselves as 1) *main informal caregivers*: caregivers of an adult(s) or child(ren) with a health problem and 2) *elderly supporters*: those providing an elderly relative over age 65 with assistance. Structured face-to-face interviews were conducted by trained local interviewers. Data were collected using a survey questionnaire (Appendix A) and the abbreviated General Health Questionnaire (GHQ) (Appendix B). Quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS), windows version. The t-test was used for all continuous data and the non-parametric Chi-Square test was used for ordinal data. Descriptive statistics were also provided.

Results: This study revealed that there was no change in the percentage of informal caregivers between phases, however, the proportion of elderly supporters decreased significantly during phase 2 ($p = 0.008$). The demographic characteristics of both phases showed that the majority of main informal caregivers were female (phase 1, 51.98%; phase 2, 56.18%) in their mid forties. In phase 2, employment increased for both main caregivers ($p = 0.001$) as well as elderly supporters ($p = 0.027$). The psychosocial health, measured by the abbreviated General Health Questionnaire, of both main informal caregivers and elderly supporters showed no significant change between both phases of the study. When comparing stress level at the time of the interviews with that of three years before the interviews, stress levels of main caregivers remained unchanged, however, stress levels of elderly supporters decreased significantly in phase 2 ($p = 0.044$). The perceived physical and mental health as well as life satisfaction of main caregivers and elderly supporters also improved in phase 2. Since informal caregiving in the Bonavista Headland was done mostly by women and although limitations exist in the study design, this research raises important questions about the health and well being of rural informal caregivers as well as the care recipients as the population of rural Newfoundland is aging much more rapidly than the rest of Canada. Furthermore, the results may have direct implications for nursing practice and policy development and provide support for the need for a more specific strategic plan to care for the elderly in this province and provide support for informal caregivers.

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This thesis is dedicated in loving memory of my father Patrick Wakeham whose youthful spirit, fearless courage and easy smile will live in my heart forever.

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CHAPTER 1

INTRODUCTION

Informal caregiving can be stressful. Research has revealed that caregiving has significant physical and psychological health consequences on the caregiver (Bedard, Koivuranta, & Stuckey, 2004; Bowd & Loos, 1996; Haley, Levine, Brown, & Bartolucci, 1987; Nijober, Triemstar, Templaar, Sanderman, & Van den bos, 1999; Tanner Sanford & Townsend-Rocchiccioli, 2004; Weitzner, McMillan, & Jacobsen, 1999; Yee & Schulz, 2000). Further, informal caregiving has been shown to negatively impact income and employment opportunities of the caregiver (Arber & Ginn, 1992; Covinsky, et al., 2001; Williams, Forbes, Mitchell, Essar, & Corbett, 2003). Past research has demonstrated that informal caregiving is dominated by women (Allen, 1994; Almberg, Jannson, & Graftstrom, 1998; Ingersoll-Dayton, Starrells, & Dowler, 1996; Neale, Ingersoll-Dayton, & Starrells, 1997) and that women's mental health is more likely to be adversely affected by caregiving than mens' mental health (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Wilcox & King, 1999; Yee & Schulz, 2000).

It has been documented that informal caregiving in rural areas is understudied and research that has been conducted on this population revealed that rural informal caregivers experience more stress, burden, and poorer physical health than their urban counterparts (Bedard, et al., 2004; Bowd & Loos, 1996; Tanner Sanford & Townsend-Rocchiccioli, 2004; Tanner Sanford, Johnson, & Townsend-Rocchiccioli, 2005; Wackerbarth, Johnson, Markesbery, & Smith, 2001)). This provides evidence to support the need for further research of rural informal caregivers.

Research has shown that the population of rural communities in Newfoundland is aging due to high rates of outmigration of young families and low fertility rates (Statistics Canada, 2006a). One such example of outmigration was as a result of the cod moratorium imposed by the Federal government of Canada in 1992, followed by the implementation of income supplementation in the form of The Atlantic Groundfish Strategy (TAGS) and subsequent end of TAGS in 1998. This had a tremendous impact on the demographic and economic landscape of many coastal communities in Newfoundland (Lilley & Campbell, 1999). Many families migrated to larger centers in search of employment. As a result, most of the informal care recipients in rural Newfoundland are seniors. Therefore, it is important to explore who is providing care to this population. The purpose of this study is to address the lack of research of rural informal caregivers by studying informal caregiving during and after TAGS in the coastal communities of the Bonavista headland region of Newfoundland.

Background

The collapse of the northern cod stocks and resultant moratorium on commercial fishing of northern cod imposed by the federal government in July, 1992 was devastating for people living in Newfoundland (Smith, 1994). The moratorium imposed on the affected fishers led to the largest job loss in Canadian history (Storey & Smith, 1995). This announcement had a tremendous impact on Newfoundlanders, as 40% of the landed fish in the province was northern cod. Approximately 10,000 fishers and 12,400 plant workers in 400 communities across Newfoundland and Labrador depended on the fishery for their livelihood, hence they were directly affected.

The moratorium of the 1990's resulted in over 30,000 Newfoundlanders and Labradoreans being unemployed, and/or with a significantly decreased income. Income supplementation in the form of The Atlantic Groundfish Strategy (TAGS) became the main source of income for many fishers and plant workers. TAGS was the financial assistance package given by the Canadian federal government to those directly affected by the fishery closure. Eligibility for this program was based on how dependant an individual was on the groundfish fishery. This was called the "duration of eligibility" and determined the length of time a person would receive financial compensation (Williams, 1996). Not all fishers and plant workers were qualified for TAGS. Criteria used to qualify for TAGS made it more difficult for some people to be eligible for this program. This was particularly true for women if they had less regular attachment to fishery related jobs due to factors such as maternity and other family leaves. TAGS was implemented in Newfoundland and Labrador in 1994 and ended in 1998. To date, this moratorium has not resulted in recovery of the northern cod stocks. Therefore, those fishers and plant workers hopeful to return to the northern cod fishery for employment will not be doing so any time soon.

The 1990's saw a tremendous outmigration of Newfoundlanders in search of employment. While Atlantic Canada saw a slow growth in population, Newfoundland and Labrador actually saw a decrease of over 15,000 population (Denton, Feaver & Spencer, 1997). This trend had significant implications for those left behind. The traditional family unit changed, as many males of households migrated to larger centers in search of employment (Lilley & Campbell, 1999). As well, many young families continued to leave coastal communities in search of employment and a better life. Outmigration from rural communities, the growing aging population and fundamental changes in the provision of health care services such as centralization of health care services, early discharge from hospital, and increased home care, has translated into an increased requirement for individuals to care in the home for family members who have chronic health problems or disabilities (Cranswick, 2004).

In 2006 seniors (age 65+) comprised approximately 13.4 per cent of the population of Newfoundland and Labrador (Table 1) and more than one third of the population was over 50 years of age (Statistics Canada, 2006a).

Table 1

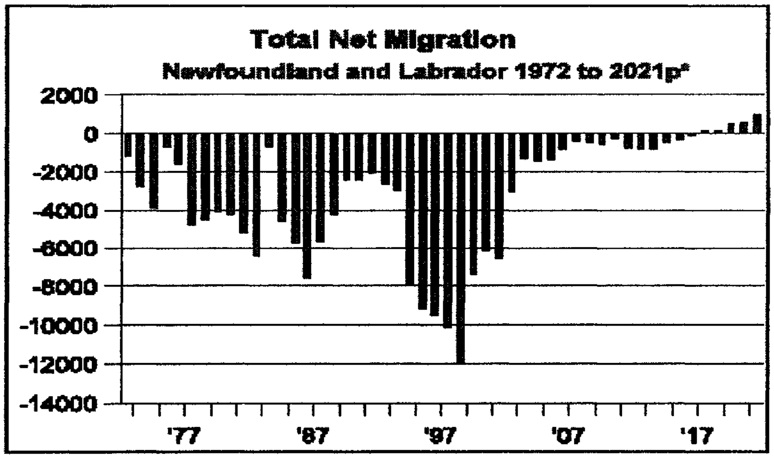
Population Estimates (2006) for Newfoundland and Labrador (Statistics Canada, 2006a).

Age Group	**Actual Number**	**Percent of Population**
50+	180,300	35.1
65+	68,800	13.4
75+	30,600	6.0
85+	7,700	1.5
All Age Groups	514,000	100

The population of Newfoundland and Labrador is aging faster than it is in the rest Canada. Three main factors are contributing to this trend. The overall aging of the population is attributed in large part to increased life expectancy. In 1951, the life expectancy at birth, for both sexes, in Newfoundland and Labrador was approximately 68 years of age. By 2001, life expectancy had increased to approximately 78 years of age; while in Canada overall, life expectancy was 80 years in 2001.

Another factor that accounts for the high proportion of seniors in the province is the low fertility rate. In Canada, generally, the total fertility rates have been in decline since the baby boom ended in the mid 1960's. However, the provincial fertility rate is even lower than it is in Canada overall (1.3 children versus 1.5 children, respectively, per woman aged 15 to 49, in 2004) (Statistics Canada, 2006b).

The third factor contributing to the aging of the population is the high rate of outmigration, especially among young people of child-bearing age in the province. Figure 1 shows the net migration from this province. As can be seen from this figure, the trend toward out-migration is predicted to continue until 2017 (Statistics Canada, 2006b).



Source: Economic and Statistics Branch, Dept. of Finance; Statistics Canada

*p=projection.

Figure 1: Total Net Migration from Newfoundland and Labrador between 1972 and projected to 2021.

Figure 1 illustrates that population loss was highest following the cod moratorium in 1992 and subsequent end of TAGS in 1998, attesting to the severe impact of this event on the provincial social, economic and demographic landscape. Again, as a result of these high rates of out-migration of young families, and low fertility rates, the proportion of seniors in the provincial population has increased much more rapidly than any other province in the country over the last 30 years. According to Statistics Canada predictions, Newfoundland and Labrador will have the highest proportion of individuals over the age of 65 in the country within ten years (Statistics Canada, 2006a). By 2016, seniors will represent almost 20 per cent of the provincial population, whereas in Canada, seniors will represent approximately 16 per cent of the population.

Table 2 shows population estimates for over age 65 by region in Newfoundland

and Labrador in 2006. As of 2006 the Clarenville-Bonavista region had 15.2% population age 65+. These population estimates were higher than that of the rest of Canada. In 2006, rural Newfoundland had a population of seniors which is predicted Canada will be within 10 years.

Table 2

Population Estimates (2006) of the 65+ Age Group in Rural Regions of Newfoundland and Labrador (Statistics Canada, 2006b).

Rural Secretariat Region	**Actual population 65+**	**Percent 65+**
Avalon Peninsula	29,856	12.2
Burin Peninsula	2,711	12.0
Clarenville-Bonavista	4,548	15.2
Gander-New-West-Valley	7,786	16.2
Grand Falls-Winsor-Bay Verte-Harbor Breton	8,388	16.2
Stephenville-Port aux Basques	4,781	15.1
Corner Brook-Rocky Harbor	6,901	15.1
St. Anthony-Port au Choix	2,148	15.1
Labrador	1,696	6.2

It has been well documented that the healthiest populations are those in societies that are prosperous and have a narrow gap between the rich and the poor (Cranswick, 2004). Over the last three decades the overall economic trend in Atlantic Canada has been characterized by increasing debt, inflation, unemployment, decreasing growth in productivity and a growing inability to afford desired levels of government services

(Lilley & Campbell, 1999). Historically, the Atlantic economy was based in rural communities and on natural resources such as the fishery, forestry, farming and mining. Reduced cod stocks have devastated the cod fishery, a cod fishery that fueled the economy for many coastal communities. People and communities were hit hard as jobs were lost in these traditional industries. The economic isolation of rural communities was accentuated as economic activity and jobs moved to urban and suburban centers. This economic reality was the main cause of the higher concentration of the elderly in rural communities. Average unemployment rates in Canada have been steadily increasing over the past decades, from close to 3% in the late 1940s, to 5% in the 1960s, and closer to 10% in the 1990s. As well the average duration of unemployment has increased from an average of 12 weeks in the 1970s, to 18 weeks in the 1980s, to more than 22 weeks in the 1990s. In Atlantic Canada the average duration of unemployment for men aged 45-64 more than doubled between 1975 and 2005 (Human Resources Development Canada, 2005). In Atlantic Canada unemployment rates are generally a third to a half greater than the rest of Canada, and twice as high in Newfoundland. Also important to note is that unemployment was especially high in rural areas and among youth, older workers and those with less formal education (Human Resources Development Canada, 2005).

According to Lilley and Campbell (1999), this change in demographics and economics, which they describe as two megatrends, will have tremendous impacts on all of the determinants of health, and hence on the well-being of all seniors as well as those who provide care to this aging population. More research, designed to better understand how the economy and population aging will affect the determinants of health, is essential to developing public policies to guide the Atlantic Provinces through the coming decades.

This study was part of a larger population health research program entitled *Natural Resources Depletion and Health* (NRDH) whose overall purpose was to assess how the health of people in Newfoundland and Labrador, and Cape Breton, Nova Scotia, that depended on natural resources had been affected by it's depletion or lessened demand for those resources. Data for the NRDH study was collected in 2001-2003, after TAGS had ended. The first set of data was collected during an interdisciplinary Eco-Research program entitled *Sustainability in a Changing Cold-Ocean Coastal Environment*, in 1995-1997, when TAGS was in place. This project was conducted in response to the closure of the northern cod fishery. It had as a primary objective to identify factors needed to sustain communities in cold ocean coastal areas (Ommer, 1998). In particular, the health section of this study explored how the northern cod fishery closure affected the health of individuals and communities in the headland of the Bonavista Peninsula and the Isthmus of the Avalon Peninsula.

There is a paucity of research examining the impact that depletion of natural resources has on health. More specifically on the health of individuals who relied on those resources for a living in Atlantic Canada and especially in Newfoundland, a province that has depended heavily on the fishery. With the closure of the cod fishery and subsequent end of TAGS coastal communities in Newfoundland saw mass unemployment and a mass exodus of young people and young families leaving the elderly and others who need care behind. In addition, research has shown that the elderly preferred to stay in their community (Lilley & Campbell, 1999). This raises the question of who is providing informal care for these seniors. Research has demonstrated that rural informal caregivers were mostly women (Morgan, Semchuk, Stewart, & D'Arcy, 2002) and that informal caregivers of working age are less likely to be employed (Cranswick, 2004). Therefore, the purpose of this study is to examine if there was any change in informal caregivers during and after TAGS using data from the Bonavista Headland area of the province, thus providing a description of these informal caregivers.

Purpose of the Study

The purpose of this study is to compare, in the Bonavista Headland, informal caregivers during the period 1995 to 1997 inclusive (during TAGS) with that of the period 2001 to 2003 inclusive (after TAGS) to determine if there were any differences in the percentage of informal caregivers, selected demographic variables, and the quality of life of informal caregivers as measured by stress level and level of life satisfaction.

Research Questions

The main research question guiding this study asks if there was any change in informal caregiving during and after TAGS in the Bonavista headland area of Newfoundland. In this study, informal caregivers contain two sub-groups: 1) main informal caregivers, and 2) elderly supporters. The definitions of these terms are listed in the next section. The specific questions are:

1. Were there changes in the percentage of informal caregivers during and after TAGS?
2. Were there changes in the demographic characteristics of informal caregivers during and after TAGS?

3. Were there changes in the stress level of informal caregivers during and after TAGS?
4. Were there changes in the level of life satisfaction of informal caregivers during and after TAGS?

Definition of Terms

There are a number of terms important to the present study. These terms and their definitions are as follows:

Informal caregiving: "Unpaid assistance, usually provided by family members, friends, or neighbors, to individuals who require care" (Schoenfelder, Swanson, Specht, Maas, & Johnson, 2000, p.47).

Main Informal Caregiver: An individual mainly responsible for taking care of an adult(s) or child(ren) with a long term illness, physical or mental condition or health problem.

Elderly Supporter: An individual providing an elderly relative, i.e., someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care.

Life satisfaction: "A desired subjective feeling indicating general well-being" (Koivumaa-Honkanen, et al., 2000).

Psychological stress: "A particular relationship between the person and the environment that is appraised as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19).

As mentioned before, in this study the definition of informal caregiver includes two subgroups: 1) main informal caregivers and 2) elderly supporters.

CHAPTER 2

LITERATURE REVIEW

The goal of this literature review is to provide an overview from published research of the factors affecting caregiving and the impact of informal caregiving on the caregiver. This review is particularly relevant to understand the characteristics of caregivers and the many challenges and potential consequences that caregivers endure especially in rural Newfoundland as they face an economic crisis due to the closure of the cod fishery. Much of the literature reviewed indicated that the majority of caregivers were women. As a result of the moratorium women were often the sole care providers as their spouses migrated to larger centres in search of employment. Women have been shown to be at greater risk for suffering health consequences as a result of being overburdened with caregiving responsibilities not only for the care recipient but also for their children and households as well (Lilley & Campbell, 1999). Other factors identified in the literature as impacting informal caregivers, and relevant to this study include, geographical location, more specifically rural location; income and employment, quality of life, and positive aspects of caregiving. Based on the literature review, a conceptual framework will be formulated to summarize the current knowledge in this domain.

Rural Caregivers

Informal care provided in rural settings is more prevalent than in most urban areas (Keefe, Fancey, Keating, Eales, & Dobbs, 2004). This phenomenon of informal caregiving within rural settings is influenced by many factors, such as the growing population of people aged 65 years and older living in rural settings, the restructuring of the Canadian health care system and subsequent regionalization of services, and the preference of many rural elders to remain within their communities (Morgan et al., 2002; Northern Secretariat of the BC Centre of Excellence for Women's Health, 2005).

The majority of caregivers within rural contexts in Canada are female. (Morgan et al., 2002). The challenges associated with providing care to an elder in a rural setting include: difficulties accessing necessary and adequate services (Morton & Loos, 1995); transportation and distance from regionalized services (Armstrong et al., 2003); and lack of awareness of available services (Morgan et al., 2002). Many rural women caregivers experience these challenges in providing care while balancing other responsibilities such as families, jobs, careers and household duties (Cuellar & Butts, 1999). The unique challenges and multiple roles impacting rural caregivers ultimately lead to burnout (Morgan et al., 2002). Therefore it is important to look at the specific context in which rural caregivers are providing care and to develop specific strategies that provide support to these caregivers. Nurses in rural settings in Canada are in key positions to offer support and assistance in order to promote the health of rural caregivers and care recipients (Rennie, Baird-Crooks, Remus, & Engle, 2000).

Defining Rural. Clarity of the term 'rural' is important because differing definitions have the potential to encompass different groups of rural people, generating discrepancies in our understanding of rural census, characteristics, culture and needs (Statistics Canada, 2001). Many articles have presented the debate of how and why rural should be defined and examine the dichotomy between defining 'rural' as a descriptive geographical location or as a social representation that reflects the socio-cultural aspects of living in rural communities (Pong, Pitblado, & Irvine, 2002; Statistics Canada, 2001; Williams & Crutchin, 2002).

Williams and Crutchin (2006) determined that the categorical definitions of 'rural' were according to land use (occupation/economic activity), population density (number of people per area squared), demographic structure (villages/towns/hamlets), environmental characteristics (degree of homogeneity), non-metropolitan areas, and commuting patterns. Stewart et al. (2002) suggested that the term 'rural' could also be used to describe the extent of a community's access to healthcare services. These authors also highlighted challenges and barriers rural caregivers, especially women, faced when accessing healthcare services therefore, their definition adds richness to defining rural.

Rural Canada. The Canadian context provided a unique view when examining rural caregivers. This unique view is rooted in the fact that over 90% of Canada's land mass is considered geographically rural (Pong et al., 2002) and just over 20% of Canadians live in rural and small towns with populations of less than 10,000 people (Rennie et al., 2000; Thomlinson, McDonough, Baird-Crooks, & Lees, 2004). It has been identified that geographic isolation is a major determinant of health among rural populations and has been recognized as such by the 2002 Romanow report on the health of Canadians (Armstrong et al., 2003).

It has been determined that caregiving in rural areas is understudied and rural caregivers are an understudied population that would benefit from future research (Tanner Sanford & Townsend-Rocchiccioli, 2004). Few data were available to document differences between caregivers living in rural and urban settings. Some data suggested that urban dwellers may be referred to specialized clinics earlier and caregivers of urban dwellers may receive more in home support long term than rural dwellers (Bedard et al., 2004; Wackerbarth, et al., 2001) and that patterns of homecare received by urban residents were typical of long-term care support whereas these patterns were more consistent with post-acute care for rural residents (Nyman, Sen, Chan & Commins, 1991). These researchers explained that post acute care provided community based services to assist people to recuperate after hospital discharge and are generally of a short-term nature. Whereas, long-term care provided a variety of care options depending on the individuals needs and were offered over an extended period of time as needed. In rural settings, services related to respite care, home health care, health promotion and illness prevention, rehabilitation, transportation and elder care facilities may not be available and, therefore not an option for rural caregivers (Bedard et al., 2004; Bushy & Liepert, 2005). Others have reported that older adults from rural regions may institutionalize prematurely in comparison to their urban counterparts (Greene, 1984); however, this issue is still being debated (Duncan, Coward & Gilbert, 1997; Penrod, 2001). Several studies have also suggested that rural caregivers received more help from informal networks than from formal resources (Bedard et al., 2004; Fast, Keating, Otfinowski, & Derksen, 2004), and that rural elders in Canada have depended more on these informal care networks than on formal services (Fast et al., 2004).

Fast et al (2004) examined the characteristics of family/friend care networks of frail seniors and found that informal caregivers in rural settings in Canada provided 80-90% of care for people greater than 65 years of age, and that although these elders had a network of family and friends working together, it is usually one individual who assumed the bulk of caring. This informal care was usually provided by a female family member and most often by daughters. These authors also found that caregiving provided by women was more frequent and involved more traditional roles, such as personal care, housekeeping and emotional support; where the care provided by men was less frequent and associated with maintenance and repair of property.

Barriers to community support faced by rural caregivers of cognitively impaired older adults have been described. These included late referral to community agencies by general practitioners and lack of information about diagnosis and dementia in general, about how to deal with behavior problems and about how to access services (Bruce & Patterson, 2000). Further, increased need for information and support from family practitioners was also mentioned in another sample (Dello Buono, et al., 1999).

Similarly, Bowd and Loos (1996) using a combination of urban and rural caregivers, identified in decreasing order of importance, needs regarding information about the care-recipient condition (>90%), regarding informal support (>60%) and formal support (>30%). It is believed that some of these specific needs would be more prevalent and difficult to surmount in rural settings.

Interested in the health of informal caregivers, Tanner Sanford and Townsend-Rocchiccioli (2004) conducted a study in rural Alabama and Mississippi that examined the differences between self-reported health status in rural caregivers and the general population. The participants were a convenience sample of 63 caregivers from rural southwest Alabama and southeast Mississippi. The mean age of the caregivers was 59 and the mean years of education was 13. The sample consisted primarily of women (78%) white (92%) and married (81%) caregivers who were unemployed (59%). Self-reported perception of health status was measured by a question that originated in the Centers for Disease Control and Prevention's (CDC) annual National Health Interview Survey, How would you rate your own health: excellent, very good, good, fair, or poor? Caregivers' health status was compared with the health status of the general population using CDC data. The rural caregivers in this study reported a statistically significant lower perceived health status than did the general population.

More recently, Tanner Sanford, Johnson, and Townsend-Rocchiccioli (2005) examined the relationships among stress, caregiver burden, and the health status of rural caregivers and assessed whether caregiver burden and stress predict the physical health status of caregivers in the rural setting. A descriptive correlational design was used to explore the caregiver health status of 63 informal caregivers in rural Alabama and Mississippi. To qualify for the study the caregiver had to provide one activity of daily living (ADL), or assist the care recipient with two instrumental activities of daily living (IADLs) and not be paid for services. Demographic data included caregiver and care recipient age, gender, ethnicity, education, and income. Caregivers were also asked questions specifically related to the rural nature of their residence. These included proximity to the care recipient, miles to the nearest hospital, miles to the care recipient's physician, and miles to the caregiver's physician. The results of this study showed that the relationships among stress, burden, and health status in rural caregivers were significantly related ($p= .000$) and significant variance in health status ($p= .000$) was accounted for by the model variables of stress and caregiver burden. Rural caregivers experienced difficulty with transportation to the hospital and their physicians, and complained of experiencing uncomfortable physical symptoms.

In a Canadian study, Bedard, et al (2004) investigated potential differences between rural and urban caregivers in the health impact on these caregivers of caring for cognitively impaired individuals. Two convenience samples of caregivers of older adults with cognitive impairment were obtained from Northern Ontario. The rural sample (n = 20) was taken from a community of < 15,000 inhabitants, the urban sample (n = 17) from a community of 125,000. The researchers obtained demographic information for caregivers and care recipients, and information regarding the level of independence in activities of daily living (ADL) and frequency of behavior problems of care recipients, the type and quantity of supports available and used by caregivers, global health indices and a measure of healthy behaviors from caregivers. Standardized instruments were used to determine care recipients' independence in ADL and frequency of behavior problems. Results showed a greater proportion of rural caregivers were non-spousal and employed. Care recipients characteristics from the 2 groups were similar, except for higher frequencies of behavior problems among the rural sample. Rural caregivers had access to fewer formal supports but did not report greater burden, poorer health status, or fewer healthy behaviors than urban caregivers. However, for rural caregivers, higher reports of burden were associated with fewer healthy behaviors ($r = 0.79$, $p = 0.001$); the researchers found no such association for urban caregivers ($r = 0.04$, $p = 0.861$).

In summary, the literature review revealed that caregiving in rural areas is understudied with few Canadian studies examining rural informal caregivers and no studies reported in Atlantic Canada. Research has shown that informal care is more prevalent in rural settings and that rural areas have an increasing population of individuals over 65 years of age. Further, rural informal caregivers were predominantly women who reported more stress, burden and physical health symptoms than their urban counterparts. The regionalization of health services in Canada has put added pressure on rural informal caregivers and has decreased their accessibility to much needed formal supports, thus putting them at an increased risk for suffering both physical and psychological health consequences.

Income/Employment and Caregiving

There is evidence in the literature documenting the considerable financial cost of caregiving. Williams, et al., (2003), identified three main sources of financial hardship. These were: the inability to take on paid work; the costs associated with the illness or disability of the care recipient; and low levels of financial assistance available to caregivers.

The impact of caregiving on the employment opportunities of caregivers has been well documented (Arber & Ginn, 1992; Covinsky et al. 2001; Williams et al., 2003). Bullock, Crawford, and Tennstedt (2003) examined the relationship between employment and caring in 119 carer dyads in the United States. They found that while employment did not affect the amount of support provided or the services used, caring did affect employment prospects of unemployed carers. Similarly, Cranswick (2004) found that in Canada caregivers of working age were less likely to be in paid employment than non-caregivers. As well, having to take time off work or alter work arrangements, such as work reduced hours, were common outcomes of the dual role of caregiver and employee.

Health Canada (2002) in the National profile of Family Caregivers in Canada final report, revealed that more than one in four caregivers indicated their employment situation had been affected by their caregiving responsibilities, either in terms of quitting/retiring early (9%) or having to make other changes in their work situation (e.g. schedules, role) (18%). Leaving a job entirely was more widely reported by women and younger caregivers looking after a younger family member (e.g. under 45 years of age). Among those currently employed, caregiving had been disruptive to their work, either to a significant (19%) or some (33%) degree. This type of impact was greater among those who had no choice in taking on the role, and among those caring for someone with a mental disability. This report also found that while many caregivers were finding it difficult to balance work and caregiving responsibilities, a majority (66%) reported they had benefited from flexibility provided by their employers, in terms of adjusting their work hours or job responsibilities in order to accommodate their caregiving duties. One in six (17%) indicated they had not benefited in this way, while a similar proportion (17%) were self-employed, therefore were responsible for their own workplace situation. Findings from this report also indicated that caregivers showed strong interest in additional workplace supports to help them balance their caregiving and employment demands. More than four in ten (42%) believed it would be very helpful to receive flexible work hours, while an equal proportion expressed a similar interest in short term job and income protection through the federal government Employment Insurance (EI) program (42%). By comparison, fewer than one in five (18%) saw a significant benefit in having access to a leave of absence without pay, likely because they could not manage without their employment income.

Statistics Canada (2002) reported on the employment consequences of giving informal care to elderly persons (aged 65 and over) for long-term health problems in caregivers aged 45 and over. For men aged 45 to 64 years 10.6% reduced hours of work; 12.8% changed work patterns; 6.7% reported lost income; and 2.4% turned down a job. For women aged 45 to 64 years, 15.6% reduced hours of work; 20.5% changed work patterns; 9.4% reported lost income; 2.9% turned down a job; and 2.4% quit a job. As retirement income is based on the number of years spent in paid employment, caregiving has a long-term as well as immediate impact on the caregiver's financial well-being.

Participation in the paid labor force has been found to have some benefits for female caregivers, despite the stress involved in juggling the demands of both activities. Schofield, Herrman, Bloch, Howe and Singh (1997) found that full-time employment was associated with fewer health problems for both caregivers and non-caregivers. Cain and Wicks (2000) found a lower level of burden in carers employed part-time compared with those not employed outside the home, or those employed full-time.

It has been argued that there is a gender difference in the impact of participation in the paid workforce on caregiver strain. For women, going to work, especially part-time work, may act as a respite from the demands of caregiving, but for men, taking on multiple roles of caregiver, father, and employee is more difficult (Arber & Ginn, 1990). Provision of support to a family member or friend who is older or who has a disability has been disproportionately done by women in late midlife, which is also the time when women's participation in the labor force is at its peak (Pavalko & Artis, 1997). However, continuing employment does not mean women are forsaking care. Because of social pressures, gender expectations, and lack of alternatives women have tended to add to their responsibilities rather than alter them. Research has shown that women with careers are no less likely to provide support than are other women (Doty, Jackson & Crown, 1998; Pavalko & Artis, 1997). There are, however, important differences between men and women who combine work and caring. Studies have demonstrated that caregiving women were more likely than their male counterparts to be employed part-time rather than full-time (Robinson, Moen, Dempster-McClain, 1995) and, compared to men who were both employed and providing care, women with these two roles had lower household incomes and were more likely to provide support for people with higher levels of cognitive and behavioral impairments. Women also reported that caregiving responsibilities were more likely to interfere with their work (Fredrickson, 1996).

Another concern that has been explored in the literature is the impact of employment on caregiving. As women's participation in the workforce increases, some authors are concerned that this will have a negative impact on their availability for care provision (Boaz, 1996; Fredrickson, 1996). However, there has been some debate about whether this is the case. Boaz (1996) compared the hours spent caregiving by non-employed and full-time employed carers in 1982 and 1989. There was not a significant difference in the hours spent caring over time but there was a difference between employed and non-employed carers in the time spent caring. This suggests that full-time employment reduces caregiving time significantly. This finding was supported in a later study by Doty et al. (1998). These researchers found that caregivers working more than 17 hours per week provided significantly fewer hours of both formal and informal support than those employed less than 17 hours per week. However, in these cases the care recipient received significantly more hours of support from other sources. Overall, care recipients of working caregivers received significantly fewer hours of support per week. These results were not supported by Bullock et al's (2003) study of African American caregivers, where employment status was not found to reduce caregiving hours.

Williams, et al (2003) examined the differences in experiences of low-income and those who were not low-income informal caregivers of frail elderly. Three hundred questionnaires were mailed to past and present home care clients in the Niagra region of Ontario. Fifty-eight completed questionnaires were returned a 19% response rate. Results showed that 65% were female caregivers and 35% were male. A significantly greater number of low-income caregivers spent more hours per day on hands on care such as dressing, toileting and feeding than did the not-low-income group. The low-income group also felt significantly more powerless, lonely, isolated, and challenged than did those caregivers who were not low income. Low-income caregivers also felt significantly less satisfied with their caregiving experience. Differences in the two groups in strategies used to relieve stress were also evident. The low-income group of caregivers used significantly more caffeine and prescription medication than those who were not low-income. On the other hand, caregivers who were not low-income more often used positive approaches to relieve stress such as socializing with friends and exercising. The low-income group also expressed a significantly greater interest in accessing financial advice than the not low-income group. They also identified their inability to access services due to limited access to transportation. As a result the low-income group expressed a greater interest in home-based services such as professional home care nursing and health care information by phone. Low-income caregivers experienced significantly greater caregiver distress than did caregivers who were not low income. These authors contend that the unique needs of low-income caregivers must be considered in the formation of Canadian eldercare policy as increased health care privatization promotes the growing inequality in health care provision.

In an American study, Kneipp, Castleman and Gailor (2004) examined the extent of informal caregiver burden in low-income women transitioning off welfare and the relationship between informal caregiving and maintaining employment. A random sample of 32 adults who had recently received welfare in a North Florida county was obtained from the State of Florida Department of Children and Family database. Sixty-three percent of participants were providing nonparental forms of informal caregiving. Caregiver burden scores among this group were highest in the time-dependence dimension of caregiving. Over 30% of participants reported having to leave a job within the past year because of caregiving responsibilities. Lack of paid sick or vacation leave and the limited flexibility of jobs women obtain after leaving welfare most directly challenged their ability to provide informal caregiving to family members or friends.

In summary, the literature review revealed that there are considerable financial and employment consequences involved in informal caregiving. Most studies reviewed were from urban areas in both Canada and the United States. Again, this highlights the gap in research examining income and employment consequences of rural informal caregivers. There is some debate in the literature regarding the effect employment has on caregiving time. Some studies reported that employment does not affect the amount of support provided by informal caregivers, while other studies reported that employment decreases caregiver support significantly. Other studies reported that full time employment reduces caregiving hours whereas part-time employment does not impact caregiving time and may act as a respite for informal caregivers. However, caregiving has been shown to affect employment prospects of informal caregivers as well as their work arrangements. Further, studies reported that employed female caregivers have lower household incomes than males and low-income caregivers as well as non-caregivers experience more stress. These findings from the research reviewed added support to the need for more studies examining rural informal caregivers as well as an eldercare policy that addresses the needs of informal caregivers.

Gender and Caregiving

Differences in caregiving between the genders are of high interest among consumers, advocates and service providers. Past research consistently has found that informal caregiving has been dominated by women who comprise nearly three-quarters of the total number of informal caregivers (Cranswick, 2004). This proportion of female caregivers was even greater among rural populations due to the expectation that women should and will assume traditional caring gender roles (Kubik & Moore, 2003). Studies have also revealed that some women felt that being a caregiver was part of being a woman (Gahagan, Rehman, Loppie, Side, & MacLellan, 2004) and that rural women may have assumed caregiving roles due to the belief that it was repayment to their parents for raising and caring for them as children (Bowder, 2002). The literature has suggested that compared with men, women were more likely to take on the role of a primary caregiver, care for a spouse or a parent, and spend considerably more hours caring for sick relatives (Allen, 1994; Almberg, et al., 1998; Dwyer & Coward 1991; Ingersoll-Dayton, et al., 1996; Neale, et al., 1997). Women were also found to provide more hands-on care with activities of daily living (ADL), the things individuals normally do for themselves in daily living such as feeding themselves, bathing, dressing and grooming, and instrumental activities of daily living (IADL), which are the six daily tasks that enable individuals to live independently in the community, these are light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, and managing money (Chumbler, Grimm, Cody & Beck, 2003; Gallicchio, et al., 2002). Studies have also shown that women's mental health was more likely to be adversely affected by caregiving than men's, as evidenced by greater feelings of burden, stress, anxiety, and depression (Gallicchio et al., 2002; Yee & Schulz, 2000). In addition to suffering from poor mental health, women caregivers tended to have exacerbated physical ailments associated with caregiving such as chronic fatigue, sleeplessness, stomach problems and weight change (Wilcox & King, 1999; Navaie-Waliser, Spriggs, & Feldman, 2002). Moreover, compared with men caregivers, women caregivers were less likely to practice health-promoting behaviors (Burton, Newsom, Schulz, Hirsh, &

German, 1997), with fewer health behaviors observed as caregiving burden intensified (Schulz et al., 1997; Sisk, 2000; Sparks, Farran, Donner, & Keane-Hagerty, 1998).

Cuellar and Butts (1999) examined caregiver distress of rural caregivers in the United States. They reported that rural women caregivers in the USA were more likely to be self-reliant, tended to refuse additional help and, depending on the dependency of the elder, may have been required to employ significant physical strength and exertion while providing care. As a result, rural women caregivers may report having poorer health than the elder for whom they are caring. These authors also found that rural women reported a rapid deterioration in their own physical health related to symptoms of persistently interrupted sleep, chronic fatigue, irregular eating habits, and numerous muscle aches. Also, in addition to these symptoms, geographical remoteness prevented many rural women from obtaining their own health care. Furthermore, because of geographic remoteness, many rural women caregivers may become immersed in the care they are providing to an elder, and ignore their own health problems, further contributing to their stress and ill health.

Bowder (2002), in a qualitative study, explored how rural women caregivers made decisions about caring for an elderly relative or friend. Women deliberating decisions differed from women implementing decisions in how they perceived their caregiving tasks and in their experience of stress. Women who implemented decisions regarding caregiving described their experiences positively and reported less stress. However, those who deliberated decisions regarding caregiving were left feeling vulnerable, doubtful about herself, and more stressed. It was found that stress and mindset affected the decision-making process of rural women, and that stress affected women's ability to problem solve and seek second opinions.

Navaie-Waliser et al. (2002), in a cross-sectional study in the United States, examined gender differences among informal caregivers in caregiving activities, intensity, challenges, and coping strategies and assessed the differential effects of caregiving on their physical and emotional well-being. Telephone interviews were conducted with a randomly selected sample of 1002 informal caregivers. Results revealed that compared with men caregivers, women caregivers were significantly more likely to be 65 or older, married, better educated, unemployed, and primary caregivers; provide more intensive and complex care; have difficulty with care provision and balancing caregiving with other family and employment responsibilities; suffer from poorer emotional health secondary to caregiving; and cope with caregiving responsibilities by foregoing respite participation and engaging in increased religious activities. These authors concluded that informal caregivers, particularly women, were under considerable stress to provide a large volume of care with little support from formal caregivers.

Chumbler, et al. (2003), examined whether there were gender and kinship (spouse, child, more distant relative) differences in caregiver burden. The study further examined the constellation of gender and kinship by examining whether adult daughter caregivers experienced greater burden compared to wives, husbands, sons, and other more distant relatives. The sample consisted of 305 family caregivers of memory-impaired individuals who were age 70 years or older and resided in non-institutional settings in Arkansas. The data used came from the Arkansas Older Adult with Cognitive

Impairment and Family Caregiver Project. A cross-sectional design was employed using validated measures to assess both the memory-impaired elders' and family caregivers' self-reported physical and memory status. Results showed that after controlling for age and health status characteristics of the memory-impaired elder, sociodemographic and health status characteristics of the family caregiver, and the caregiver coping response (measured by the sense of coherence), multiple regression analyses found kinship, but not gender differences in caregiver burden. Adult children experienced more caregiver burden than more distant relatives. There were no significant differences in caregiver burden between adult children and spouses. Adult daughters had greater caregiver burden scores compared to more distant relatives, but had comparable scores to wives, sons, and husbands. Other significant correlates of burden included caregiver personal characteristics (age and ethnicity) and the sense of coherence. The authors contended that this study clearly indicated a need for programs to help relieve adult children and daughters of the stress experienced in managing households as well as caring for impaired relatives in their homes.

Gallicchio et al. (2002) conducted a study to examine the relationship of gender with depression and burden among informal caregivers of dementia patients in a population-based study that included spouses, adult children, and other caregivers. This study was a secondary analysis of an existing data set from the Canadian Study of Health and Aging, a multicenter study of the epidemiology of dementia, health, disability, and well-being among Canadians aged 65 years and over. Data from 259 female and 68 male caregivers were analyzed. Depressive symptoms were measured using the Centre for

Epidemiologic Studies-Depression Scale (CES-D). Burden was assessed using Zarit's Burden Interview. Associations between the outcome variables (depressive symptoms and burden) and the independent variable, gender, were examined using logistic regression. In multivariable analysis, results showed that female caregivers were found to have significantly higher odds than male caregivers of having a score of 33 or higher on Zarit's Burden Interview. Poor perceived caregivers' health and more behavior disturbance in the patient were associated with significantly higher odds of high levels of caregiver burden and depression. Although gender was the major study variable, the association of depression and relationship to the patient was also examined. Similar to Chumbler et al (2003), findings revealed that spouses and children of the patient had significantly higher odds of a high CES-D score than other caregivers. These researchers concluded that adequate assistance must be given to women caregivers to ensure that they were not strained beyond what was clinically healthy. In addition, interventions should target caregivers of behaviorally disturbed patients as well as caregivers who report poor physical health to reduce the negative psychological impact of caregiving.

A review of the association between gender and psychiatric morbidity was published by Yee and Schultz (2000). These researchers found that the majority of studies on depression and burden in caregiving found higher levels of both in female caregivers when compared to male caregivers. It should be noted that the review included literature on informal caregivers not only of dementia patients, but also of other mentally or physically disabled elders as well. Most studies reported in the review were conducted using spousal caregivers, and did not include adult child caregivers or other relative caregivers. In addition, many of the studies that reported gender differences in psychiatric morbidity were cross-sectional. As a result, the differential effects of caregiving on men's and women's psychiatric symptomatology over time are not clear (Yee & Schultz, 2000).

More recently, Pinquart and Sorensen (2006) in a meta-analysis, integrated results from 229 studies on gender differences in caregiver psychological and physical health, caregiving stressors, and social resources. Women reported higher levels of burden and depression, and lower levels of physical health and subjective well-being than did caregiving men. However, when analyzing specific caregiving tasks, these authors found that significant gender differences emerged only for personal care.

Yee and Shulz (2000) in their review of gender differences in psychiatric morbidity among family caregivers further compared caregiver depression scores with age-matched noncaregiving community samples. The results of most studies reviewed indicated that women caregivers tended to report higher levels of depression, anxiety, and general psychiatric symptomatology and lower levels of life satisfaction than men caregivers. In addition, it appeared that the excess psychiatric morbidity among women caregivers was in part attributable to the caregiving experience, as evidenced by the larger difference between depression scores of women caregivers and comparable noncaregiving female community samples when compared with the difference in depression scores of men caregivers and comparable noncaregiving male community samples.

In summary, research has consistently shown that informal caregiving has been dominated by women. This finding was even greater in rural areas where it was expected that women would assume traditional caring roles. Rural informal caregivers were most often spouses and adult daughters who have been consistently shown in research to experience greater burden, stress, depression, and poorer physical health than more distant relatives and friends. It is evident that rural female informal caregivers have been under considerable stress; research has clearly demonstrated the need for policies and programs to support the needs of rural informal caregivers.

Quality of Life and Caregiving

Quality of life (QOL) is a construct that encompasses health and functioning, socioeconomic status, psychological, emotional and spiritual aspects, and family relationship (Ferrans, 1990). Although some scholars have demonstrated different points of view regarding the dimensions of QOL, most researchers generally agreed that QOL is multidimensional, subjective, and related to a state of physical, psychological, social and spiritual well-being (Zebrack, 2000). However, QOL for caregivers has been shown to include more aspects such as burden and family functioning (Edwards & Ung, 2002). Further, some researchers have used QOL together with life satisfaction, adaptation, health and distress (Cameron, Franche, Cheung, & Stewart, 2002; Haley, et al., 1987; Pot, Deeg, & Dyck, 2000; Wallhagen, 1992). Such comprehensive consideration has led to an awareness of QOL as a broader and more appropriate concept for determining how caregiving affects family members (Canam & Acorn, 1999).

Factors influencing caregivers QOL have been identified in the literature as patient characteristics, caregiver characteristics and primary and secondary stressors. Primary stressors have been identified as caregiving demands, patient impairment, the duration and intensity of care, ADL dependency, stressor types, and caregiver overload, how much assistance is given the caregiver, recurrence of illness and problem behavior in the care recipient. Secondary stressors were caregiving demands, role change, responsibility, caregiver experience, and lifestyle interference. Other factors included stress appraisal, stress coping methods and social support. Research investigating the relationship between types of stressors and caregivers QOL has demonstrated inconsistent results.

Vedhara, Shanks, Anderson and Lightman (2000) investigated chronic caregiver stress, more specifically the role of stressors and psychosocial variables in the stress process. Stress response was measured by 1) the savage personality screening scale, which measured anxiety and depression and 2) the global measure of perceived stress which was used to measure stress. Findings revealed that primary stressors were related to reductions in caregiver QOL. Similar findings were reported by Winslow (1997) in his research on stress outcomes of family caregivers of Alzheimer's patients. Stress outcomes included yielding of the caregiver role, decreased physical health of the caregiver and increased anxiety. In contrast, Nijboer et al. (1999) explored the determinants of caregiving experiences and mental health of partners of cancer patients. They investigated caregiver characteristics (income, quality of relationship, initial depression and initial life satisfaction) and patient characteristics (depression). Depression was measured by the 20-item center for epidemiologic studies depression scale and life satisfaction was measured by the 1-item linear visual analogue self-assessment scale. These researchers did not find any association between primary stressors and caregivers

QOL. Boyle et al. (2000) found a significant relationship between secondary stressors and QOL in their examination of caregiver quality of life after autologous bone marrow transplantation. Significant predictor variables included the demands of role change, increased responsibility and decreased support. These researchers used an 8-item, open – ended questionnaire to measure the outcome variable of life satisfaction. In contrast, Nijboer et al. (1999) found that secondary stressors were unrelated.

Weitzner, et al (1999) explored family caregiver QOL looking specifically at differences between curative and palliative cancer treatment settings. They examined the association between patient characteristics (including, performance status, gender, age, depression, type of illness, pain and symptoms) and caregiver QOL. QOL was measured using the caregiver quality of life index-cancer. Results showed that the patient's performance status, type of illness and depression were related to the caregiver's QOL. However, Nijober, et al., (1999) in their study of the determinants of the caregiving experiences and mental health of partners of cancer patients showed that pain and physical symptoms were not related to caregiver QOL.

Winslow (1997) studied the effects of formal supports on stress outcomes in family caregiver's of Alzheimer's patients. The association between the caregiver's age and QOL was examined. The results revealed that older age of the caregiver was associated with increased stress. Janes and Peters (1992) reported similar findings in their research exploring the effects on the carer's QOL of caring for elderly dependants. The outcome variable QOL was measured by the variables stress, anxiety, depression, and health. These researchers also found that female caregivers were more likely to be depressed.

Haley, LaMonde, Han, Burton, and Schonwetter (2003) studied predictors of depression and life satisfaction among spousal caregivers in a hospice setting using a stress process model. Forty caregivers of dementia patients and 40 caregivers of patients with lung cancer were recruited from a non-profit hospice in Tampa, Florida. The patient's spouse had to be the primary caregiver. Their results suggested that objective measures of patient impairment or amount of care provided were not strong predictors of caregiver depression or life satisfaction. Female gender, caregiver health problems and negative social interactions were risk factors for poorer caregiver well being. Caregivers who subjectively appraised caregiving tasks as less stressful, who found meaning and subjective benefits from caregiving and with more social resources had lower depression and higher life satisfaction. As well correlational analyses revealed that wives had higher depression and lower life satisfaction than husbands. In addition, high life satisfaction was associated with higher educational attainment and income.

In summary, research studies have consistently shown that informal caregiving affects the QOL of informal caregivers. However, research investigating the relationship between stressors and informal caregivers QOL has demonstrated inconsistent findings. Primary stressors, such as caregiving demands, patient impairment and duration and intensity of care and secondary stressors such as role change, responsibility, caregiver experience, and lifestyle interference and their relationship to informal caregivers QOL have been examined by many researchers. Some studies revealed that primary stressors were related to reductions in caregivers QOL, while others did not report such an association. Further, while some researchers found significant relationships between secondary stressors and decreased QOL of informal caregivers others found that secondary stressors were unrelated.

The inconsistent results in the literature and research reviewed clearly demonstrated that caregiver QOL is multidimensional and subjective. This must be considered when developing strategies to support informal caregivers.

Positive Aspects of Caregiving

There has been a tendency within the research community to view caregiving in pathological terms. Instruments for measuring stress appear to be far more prevalent than those concerning the rewards or 'uplifts' of caregiving (Nocon & Qureshi, 1996). More recently, there has been a growing research interest in the rewards and gratifications of family caregiving, often described in anecdotes, vignettes, and detailed accounts told or written by families themselves. Such rewards can emanate from aspects of the caregiving role itself through intrapersonal qualities (e.g. strengthened faith, tolerance, personal growth, skill development and career expansion), and interpersonal qualities (e.g. strengthened family ties and expanded social networks) (Clifford, 1990; Greenberg, Seltzer, & Greenley, 1993; Turnbull, et al., 1993; Vernooij-Dassen, Persoon, & Felling, 1996).

In order to better appreciate the caregiver experience it is important to understand how the positive aspects of caregiving relate to the negative consequences such as burden and depression. Cohen, Colantonio and Vernich (2002), examined the positive aspects of caregiving and how they were associated with caregiver outcomes in a sample of caregivers derived from the Canadian Study of Health and Aging. A sample of 289 caregivers caring for seniors living in the community was questioned about their experience of caregiving. Caregivers were asked whether they could identify any positive aspects related to their role, the type of positive aspects and to rate their feelings about caring. The researchers used Noonan and Tennstedt's (1997) conceptual model of meaning in caregiving. Results showed that 211 caregivers (73%) could identify at least one specific positive aspect of caregiving. Most reported caregiving as self-affirming. An additional 20 (6.9%) could identify more than one positive aspect. Positive feelings about caring were associated with lower CES-D scores ($p < 0.001$), lower burden scores ($p < 0.001$) and better self assessed health ($p <0.001$). These authors concluded that clinicians should inquire about the positive aspects of caregiving if they are to fully comprehend the caregiver experience and identify risk factors for negative caregiver outcomes.

Kristensson Elkvall (2004) in a Swedish study on caregiving to the elderly pointed out that there are caregivers who, despite the extensive care they give, find satisfaction in the caregiving situation and seem to have a functional way of coping with the difficulties of the care. Similarly, Lund (1999) in a study using the Carers' Assessment of Satisfaction Index (CASI), a 30-item score index which explores the range and diversity of caregiver reward, found that the majority of caregivers experienced some feelings of reward.

Andren and Elmstahl (2005) conducted a study to explore a previously developed instrument to study rewards gained by caregivers and to determine the factors associated with satisfaction in family members caring for patients with dementia living at home. A sample of 153 individuals participated. The main finding of this study was that a high proportion of caregivers expressed satisfaction, irrespective of the burden on, and the health of, the caregiver. Stress factors and satisfaction can coexist and relate to different aspects of the caregiver situation.

Qualitative researchers identified the construct "finding meaning" in caregiving. Farran, Keane-Haggerty, Salloway, Kupferer and Wilkins (1991), conducted a study of caregivers of patients with dementia and found six themes that led to finding meaning as a positive psychological resource variable in caregiving. These qualitative data were later used to construct a quantitative scale, The Finding Meaning through Caregiving Scale, for use in assessing positive aspects of, and ways of finding meaning, through caregiving (Farran, Miller, Kaufman, Donner, & Fogg, 1999). This measure has three subscales: Loss/Powerlessness, which identifies difficult aspects of caregiving; Provisional meaning, which identifies how caregivers find day-to-day meaning; and Ultimate Meaning, which identifies philosophical/religious/spiritual attributions associated with the experience of caregiving. An earlier study by this group showed that subjects who were able to find higher levels of meaning had lower depression scores (Farran, Miller, Kaufman, & Davis, 1997).

In summary, studies have shown that informal caregiving can be a positive and rewarding experience. Researchers have consistently found that informal caregivers who are able to identify positive feelings about the caregiving experience showed lower depression scores, lower burden scores, and better self-assessed health. Further, it has been identified that stress and satisfaction with the caregiving experience can coexist.

Appropriate and timely supports for informal caregivers may help them find meaning in the caregiving experience, thereby, reducing the risk of negative health outcomes.

Summary

In conclusion, this literature review revealed that there is limited research that examines issues of rural caregivers, especially women, who make up 70% of the caregiver population, and who reside within rural contexts in Canada. Nevertheless, the available literature revealed that rural women caregivers were faced with several challenges when providing care. Many of these challenges were associated with accessing adequate and appropriate healthcare services, geographical distances from regionalized centers and health services, culturally incongruent health care, social/geographical isolation and transportation challenges. In addition to these issues, many rural women were faced with multiple role demands of being a wife, mother, caregiver and employee. These factors have left rural women caregivers susceptible to additional stresses and burnout, with limited resources on which to depend. Informal caregiving has been shown to negatively impact employment and income opportunities of the caregiver, however, as evidenced in the literature, employment, especially part-time has been linked to reduced caregiver stress and acts as a respite for the caregiver. Informal caregivers have also been shown to extract positive experiences from informal caregiving often described as rewards and gratifications. As well, studies have shown that stress and satisfaction can coexist in the caregiving experience. More research into these concepts may help predict negative outcomes in caregivers and provide the insight necessary to develop strategies to plan care for care recipients as well as their caregivers.

Conceptual Framework

The conceptual framework for this study is based on findings from published research investigating concepts impacting the caregiving experience of informal caregivers. It is not feasible to study all factors that can potentially impact caregiving. This study will describe and compare informal caregiving in a rural Newfoundland community (namely The Bonavista Headland) during and after The Atlantic Groundfish Strategy (TAGS) as well as describe the demographic characteristics, life satisfaction, and stress level of informal caregivers during these two time periods. The northern cod fisheries closure is viewed as the stimulus that caused the economic crisis. This crisis has caused loss of jobs for some individuals (Storey & Smith, 1995) and for others it has caused reduced job security (Department of Fisheries and Oceans, 1993). As a result of the crisis, individuals were experiencing increased stress and lower socioeconomic conditions. The 1990's saw a tremendous outmigration of Newfoundlanders from coastal communities in search of employment (Denton et al., 1997). However, it has been documented that seniors preferred to stay in their communities resulting in the rapid aging of rural communities (Lilley & Campbell, 1999). This raises the question of who are the informal caregivers providing care to this population. The change in demographics and economics of rural Newfoundland will have tremendous impacts on all the determinants of health, and hence on the well-being of seniors as well as those who provide care to this aging population.

This study investigates whether there was any change in informal caregivers during and after TAGS and provides a profile of who the caregivers are by answering the following research questions:

1. Are there changes in the percentage of informal caregivers during and after TAGS?
2. Are there changes in the demographic characteristics of informal caregivers during and after TAGS?
3. Are there changes in the stress level of informal caregivers during and after TAGS?
4. Are there changes in the level of life satisfaction of informal caregivers during and after TAGS?

Figure 2 depicting the conceptual framework outlines select sociodemographic characteristics of the informal caregiver that have been shown in published research to impact the caregiving experience. This experience in turn has been shown to impact the quality of life of the caregiver. Quality of life has been reported to encompass the concepts of life satisfaction, physical and mental well-being, and stress level. High levels of stress and poor quality of life in turn have been shown to affect the level and quality of caregiving. Studies have demonstrated that the caregiver can extract rewards and gratifications from caregiving, and that stress and satisfaction can coexist in the caregiving experience, hence the two-way arrow depicting these findings. The select sociodemographic characteristics as well as the quality of life of the informal caregiver were measured at two time periods, during and after TAGS.

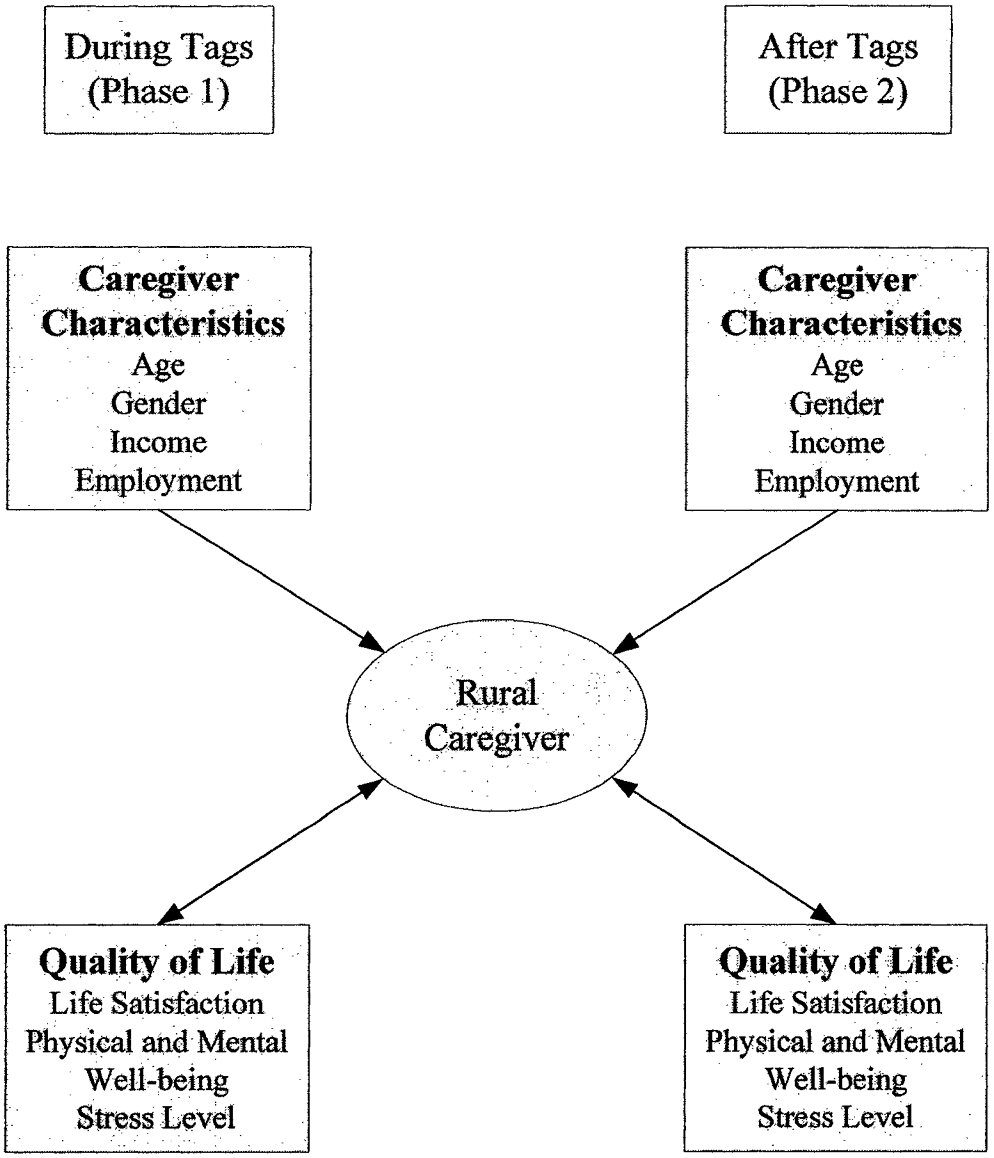


Figure 2. Conceptual Framework: Factors Affecting Rural Informal Caregivers.

CHAPTER 3

METHOD

This chapter describes the setting, the study design, the sample and instruments used, data analysis and ethical considerations.

Setting

The Bonavista headland is a region of the north-east coast of the island of Newfoundland. In 1991 this area had a population of approximately 30,000 residents (Newfoundland Statistics Agency, 1995). As this area is exposed to the Labrador Current the climate is harsher than other areas of similar latitudes as evidenced by higher rainfall, a slower increase in temperatures in spring and early summer, a slower decrease in temperature in autumn and milder winters. Non-native populations settled this area over 500 years ago and since this time the fishery has played a large role in the economic structure of the Bonavista headland communities. Since Newfoundland joined Canada in 1949 the fishery in this area has become more industrialized as seen in large fish plants in the communities of Bonavista and Catalina (Ommer, 1998). The majority of the residents of this area were dependent on the fishery as a source of employment therefore the depletion of the northern cod stocks and the subsequent moratorium caused many residents to lose their livelihood.

Newfoundland has a history of high unemployment, especially in rural coastal areas that are adversely affected by seasonal employment. Census data compiled before and after the moratorium illustrate the effects of the moratorium on local unemployment rates. According to Statistics Canada (2004) unemployment rates fluctuated from before the moratorium to after the moratorium but it was generally higher than the provincial average. Unemployment in Newfoundland in general decreased from 27.8% in 1991 before the moratorium to 25.1 % in 1996 to 21.8% in 2001. In the Bonavista Headland unemployment decreased from 51.9% in 1991 to 42.3% in 1996 to 32.7% in 2001. As job availability in the rural Newfoundland was generally low and a number of displaced fishery workers were receiving financial compensation during The Atlantic Groundfish Strategy (TAGS) and thus not included in the unemployment statistics. Decreases in the unemployment rates were most likely due to a decrease in the number of people looking for work and high outmigration of unemployed individuals to search for jobs outside of Newfoundland.

Design

This study was part of an ongoing three-year funded population health research program entitled *Natural Resources Depletion and Health.* This project's overall purpose was to assess how the health of people in Newfoundland and Labrador and Cape Breton, Nova Scotia, that depended on Natural resources had been affected by the depletion of those resources (Gien et al., 2002).

The study involved a secondary analysis of data collected during two time periods. The data were collected in the same geographic area at both time periods, using a cross-section of the population. The first set of data was collected in 1995-1997, during the first study *Eco Research – Health Survey* while individuals affected by the cod moratorium were receiving income support through TAGS. The second set of data was collected in 2001-2003, during the *Natural Resources Depletion and Health* study after the TAGS program had been completed. This study used a non-experimental, retrospective design to attempt to answer the research questions.

Sample and Instruments

The main sources of data were residents from Bonavista. During phase 1 in 1995, 681 people were randomly selected using residential telephone numbers from the Bonavista Headland area while during phase 2 in 2002, 671 people were randomly selected from the same area. The samples represented about 9% of the people from Bonavista.

The first study (phase 1) was an interdisciplinary Eco-Research program entitled "Sustainability in a Changing Cold-Ocean Coastal Environment," which assessed the impact of the fishery closure on various aspects of individuals and communities in two coastal Newfoundland community areas. The second study (phase 2) was another interdisciplinary study titled "Natural Resource Depletion and Health" an international study which assessed the effect of natural resource depletion on the health of both individuals and communities. The Newfoundland component examined the effects of TAGS termination on various aspects of individuals and communities and was a follow-up of the first study. Bonavista was sampled during both phases of the study. Data for Phase 1 were collected in 1995 during the period that TAGS was available for several years. Phase 2 was a post-TAGS study in 2002-2003. The health section of the larger Eco-Research program assessed the impact of the fishery collapse on the health of the people living in the affected areas.

The questionnaire (Appendix A) used for the Eco Research Health Survey

(ERHS) was developed to assess the health status of the participants. A team of researchers designed it with expertise in nursing and community health. In order to establish content validity, a larger team of researchers working on the Eco-Research project critiqued it. Minor changes were made to the ERHS after a pilot test in a Newfoundland community with similar characteristics to that of the studied areas. The ERHS was used in this study to collect data on demographic variables, mental health in the past three years, sources of stress, domain satisfaction, feelings of uncertainty, and financial strain.

Following approval of the Human Investigation Committee at Memorial University of Newfoundland household telephone numbers were randomly selected from the telephone directories for the two phases of the study. For the first study, six trained local interviewers contacted potential participants by telephone. All individuals aged 16 and over, in the households that were contacted, were asked to participate. In the spring of 1995, structured face-to-face interviews were conducted in the respondent's residence, which lasted from 45 minutes to over an hour. Respondents were paid $10 per completed interview.

Most households in rural Newfoundland have a telephone and very few of their numbers are unlisted. As such, the usual biases associated with telephone surveys such as the exclusion of those without a phone, the homeless, and those with unlisted numbers were not a factor in this study. Trained local interviewers interviewed all selected participants individually. Such an interviewing strategy reduces inaccuracies and biases that may result from depending upon a small subset of household members (usually only one) for information on all household members (Anderson & Silver, 1986). Institutionalized individuals were not included in the study. The sample represented a cross section of adults of various ages and occupations.

Data were collected using the following instruments:

1. *Survey questionnaire* (Appendix A) consisted of structured and open ended questions designed by the researchers, with input from experts in the field, assessing stress level, satisfaction with life, education, financial status, and a wide range of health indicators such as use of alcohol, medications, cigarette smoking and other coping measures. Residents' perceived impact of the fishery closure on their health, their family and communities are also explored. Relevant questions used in the two national health surveys (Health and Welfare Canada, 1993; Statistics Canada, 1997) were included (with permission) to facilitate comparison. These latter questions had been pilot-tested with at least 600 Canadians before their use for the national sample of 13,000 participants in each survey. Minor revisions were made so that it was relevant to the selected community and to the time frame used in this study (Gien et al., 2002). The questions on caregiving were designed by the research team members with expertise in the subject. They were reviewed and critiqued by the larger interdisciplinary team before pilot testing with 30 rural residents in areas affected by the cod moratorium. The pilot sample was not in the community involved in this study and therefore, was not included in the studied sample.

2. *The abbreviated General Health Questionnaire (GHQ-28)* (Appendix B) measured changes in emotional states among respondents in the community settings and non-psychiatric clinical settings. It had two main uses: to estimate the prevalence of illness in

a particular population and to pick up cases of "hidden psychiatric illness". The GHQ was intended to be culture specific and has been used in many previous studies on unemployment in various countries (Goldberg & Williams, 1988). It was considered as the most thoroughly tested tool with well-established reliability and validity. The test-retest coefficient after six months was .90 and split-half reliability was .92. Inter-rater reliability for 12 interviewers showed a disagreement on only 4% of symptom scores. Furthermore, the sensitivity for the GHQ-28 was 85.6% at a specificity of 86.8% (Kline, 1993; McDowell & Newell, 1987). It had four subscales: somatic symptoms (GHQA), anxiety/insomnia (GHQB), social dysfunction (GHQC) and depression (GHQD). The items referred to feelings or behaviors and had a four-point scale demonstrating the extent of the feeling or behavior (Kline, 1993). The range of possible scores was 0 to 21 for the subscales and 0 to 84 for the GHQ-28 as a whole. A higher score for the GHQ denoted more psychological distress. Both questionnaires 1 and 2 above were pilot-tested and used in previous studies in Newfoundland with no major difficulty (Gien et al., 2002).

Data analysis

Quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS), windows version. Descriptive statistics were provided for all groups on all continuous data measures including the four sub-scales of the GHQ, life and domain satisfaction measures, and stress and health measures.

The sample consisted of participants who answered two questions related to caregiving. The two questions were designed to collect data about caregiving, which were used to create the sample needed to analyze the data for differences in caregiving between the two phases of the cod moratorium. One question, question 30 (Appendix A), involved individuals who were mainly responsible for taking care of an adult(s) or child(ren) with a long-term illness, physical or mental condition or health problem. The other question, question 32 (Appendix A), involved individuals who were currently providing an elderly relative, i.e., someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care. Both questions examined caregiving during and after TAGS. Were there phase differences in the percentage, gender, the income/employment status, stress level, and life satisfaction of informal caregivers?

Continuous data were analyzed using a one-tailed t-test procedure to identify differences in informal caregivers between two time periods with a level of significance set at $p<0.05$. This test was used as the two samples, were independent and randomly selected (Polit & Beck, 2004). Data were of Likert scale which met the criteria for the t-test as perceived health were scored from 1 (very unhealthy) to 7 (very healthy) and stress level were scored from 1 (much less stressful) to 5 (very stressful). This parametric test is more powerful, flexible and robust and thus are not influenced by violations of the assumptions (Nieswiadomy, 1998).

Nominal data were analyzed using a non-parametric test of group differences (Chi-Square). The Chi-Square test is a non-parametric procedure used to test hypotheses about the proportion of cases that fall into different categories when the dependent variable is on a nominal scale. Nominal data (yes/no answers) were analyzed using Chi-

Square. Some data such as employment status were recoded into nominal data, for example employment status was recoded into 5 variables; Are you employed? Are you unemployed? Are you retired? Are you keeping house? Are you a student?

Some data were recoded to reflect the general tendency of the questions from less to more. For example most questions answers were from less happy, less stress etc. to more happy, more stress. A few question answers went from more to less so those answers were recoded to also go from less to more. For example question 30d coded very stressful as 1, while not at all stressful was coded as 4. Questions 12 and 13a were also recoded. There was one qualitative question included, question 32d (Appendix A), which asked respondents to describe the reason for any change in assistance/caregiving activities in the past three years.

The blending of quantitative and qualitative data collection, the use of a variety of data sources, and of investigators described above reduces the possibility of errors of a biased or one-side interpretation, avoids the limitations of a single approach, and will strengthen the validity and meaningfulness of findings. Furthermore, this multimethod research could lead to substantive insights into the complex and multidimensional nature of issues under study (Polit & Beck 2004).

Data relevant to the effect of caregiving on study participants (Appendix A) and the questionnaire sub-totals of the abbreviated General Health Questionnaire (Appendix B) were analyzed using the t-test. Responses on these measures by the current sample of participants could be compared with the scores prior to the withdrawal of TAGS.

While interpreting the results, some study limitations should be noted. Although every effort was taken to ensure the accuracy of responses from the participants, some limitations of this study are as follows: (a) generalization of the results beyond the study sample may not be possible as the community context of the study area may be different than that of other communities in Newfoundland; and (b) the information expressed may represent the participant's perception at the time of the interview only and does not reflect changes over time. Despite the limitations cited above, the use of a large random sample would have minimized error and improved the validity of the findings.

Ethical Considerations

Even though this study, using secondary data analysis, did not involve face-to-face contact with participants to obtain data from them, it did involve information pertaining to human subjects and therefore it was important to consider the ethical aspect of the study. The Tri-Council guidelines on ethical conduct in research involving humans requires that research using confidential information are considered and approved by an ethical review board (Tri-Council, 1999). Consequently, the research proposal for the study and plans for protection of information were submitted and received ethical approval from the Human Investigation Committee of the Faculty of Medicine of Memorial University of Newfoundland prior to obtaining access to the data.

One of the major ethical considerations when utilizing confidential information on individuals is the protection of this information. Therefore, a number of measures were taken to protect the anonymity of the individuals whose responses formed the data set. The researcher did not have access to identifying data (names or addresses). The data were stored on a computer diskette and was only available to this researcher and supervisor in order to maintain confidentiality of the individuals in the communities under study. The copy of the data on the diskette will be returned to the researcher's supervisor.

CHAPTER 4

FINDINGS

This chapter presents the results for both main informal caregivers: those mainly responsible for taking care of an adult(s) or child(ren) with a long term illness, physical or mental condition or health problem; and elderly supporters: those providing an elderly relative, someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care, during and after The Atlantic Groundfish Strategy (TAGS). First the demographic characteristics of both phases are provided to give an overview of the demographic picture and set the context for interpreting the data. Results are then outlined under the following headings; percentage of informal caregivers, demographic characteristics, psychosocial health, stress level, and life satisfaction for the two time periods. Significant results are presented in bold.

There were two questions in the questionnaire involving caregiving that were used to answer the research questions. Question 30 (Appendix A) involved individuals who were mainly responsible for taking care of an adult(s) or child(ren) with a long-term illness, physical or mental condition or health problem. These are *main informal caregivers* in this study. Question 32 (Appendix A) involved individuals who were currently providing an elderly relative, i.e. someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care. These are *elderly supporters* in this study. These two groups of informal caregivers were analyzed separately due to the unique situation in coastal Newfoundland communities which have an increased population of seniors due to outmigration. More specifically, the Clarenville-Bonavista region as of 2006 had a 15.2% population age 65+ (Statistics Canada, 2006b). Therefore, it was important to provide a description of the informal caregivers of this aging population.

Demographic data for the total sample of Bonavista (Table 3) during both phases of the study indicated a significant increase in the mean age of the community residents ($p<0.000$) during phase 2 and a significant increase in individual income ($p<0.000$) but household income was stagnant which may indicate that households were smaller in phase 2 than in phase 1. Phase 2 also saw a significant increase in employment and decrease in unemployment, as well significantly more individuals classified themselves as keeping house.

Table 3

Demographic Characteristics of the Sample in Bonavista during Both Phases

	%	**Phase 1** Mean *n=681*	(S.D.)	%	**Phase 2** Mean *n=671*	(S.D.)	**t-test** *p=0.05*	**Chi Square** *p=0.05* df = 1
Age		43.26	(17.34)		47.22	(17.11)	**0.000**	-
Male	48.02			43.82			-	0.121
Age		42.81	(17.03)		47.98	(16.25)	**0.000**	
Female	51.96			56.18			-	0.121
Age		43.68	(17.63)		46.63	(17.75)	**0.025**	
Employment Status								
Employed	22.03			40.24			-	**0.000**
Male	19.57			43.54				**0.000**
Female	24.29			37.67				**0.000**
Unemployed	40.97			16.54			-	**0.000**
Male	53.21			22.79				**0.000**
Female	29.66			11.67				**0.000**
Retired	17.77			16.39			-	0.518
Keeping house	11.16			19.22			-	**0.000**
Student	8.08			7.3			-	0.604
Income - Household	3.45		(1.46)	3.41		(1.50)	0.747	-
Income - Individual	1.71		(0.92)	1.99		(1.06)	**0.000**	-

Percentage of Main Informal Caregivers and Elderly Supporters During and After TAGS

Research question 1: Is there a change in the percentage of informal caregivers during and after TAGS?

The percentage of individuals who identified themselves as main informal caregivers: those mainly responsible for taking care of an adult(s) or child(ren) with a long term illness, physical or mental condition or health problem was similar in both phases. Table 4 revealed that during phase 1 of the study 5% identified themselves as caregivers of a person(s) with a long-term health problem and during phase 2, 3.87% identified themselves as such.

In addition to main informal caregivers, this section describes individuals who were not main informal caregivers but were elderly supporters: those who provided an elderly relative i.e. someone over 65 years old, with financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care, question 32 (Appendix A). According to the definition of informal caregiving, this group is also considered informal caregivers. However, the survey questions dealing with caregiving differentiated these two groups, which provided a more detailed description of informal caregivers. Results indicated that more people provided an elderly relative with some type of support than being mainly responsible for caring for an ill adult or child. During phase 1, 16.15% of the sample identified themselves as providing support to a relative 65 or older. During phase 2, 11.18% identified themselves as such. The level of support for the elderly decreased significantly during Phase 2 (Table 4).

Table 4

Percentage (%) of Main Informal Caregivers and Elderly Supporters for Both Phases of the Study

	Phase 1 *n=681*		**Phase 2** *n=671*		**Chi-Square** *p = 0.05*
	%	*n*	%	*n*	df = 1
Main Caregiver	5.00	34	3.87	26	0.315
Elder Support	16.15	110	11.18	75	**0.008**

Table 5 provides the mean age of care recipients and the percentage of adults and children being cared for. There was no phase difference for age with most people receiving care being adults.

Table 5

Informal Care Recipients during Both Phases of the Study

	Phase 1 *n* = 34		**Phase 2** *n* = 26		**t-test** *p = 0.05*
	Percent	n	Percent	n	
Adult	76.47	n = 26	96.15	n = 25	0.610
Child	23.53	n = 8	3.85	n = 1	

Before analyzing the relationship of care recipient to caregiver data were regrouped to decrease groupings and increase *N* within the groups. For example mother and father were recoded to parent, son and daughter to child etc. Table 6 shows the relationships during both phases. Chi-Square analysis was performed to identify between phase differences. The only significant difference was found for the non-relative category. During phase 1 no one was providing care for a non-relative however, during phase 2 almost half of the recipients of care were not related to the caregiver.

Table 6

Relationship of Care Recipients to Main Informal Caregivers

	Phase 1 *n* = 34 %	Phase 2 *n* = 26 %	Chi - Square *p = 0.05* df =1
Spouse	32.35	15.38	0.133
Child	17.65	3.85	0.099
Parent	29.41	11.54	0.096
Grandparent	5.88	11.54	0.432
Other relative	14.71	11.54	0.721
Non-relative		46.15	**0.000**

There was surprisingly little overlap, considering the definition of informal caregiving, between those who identified themselves as main informal caregivers and those who provided assistance for an elderly relative with only 17.2% of the caregivers classifying themselves in both groups.

The number of people over 65 that respondents had contact with or who might turn to them for help did not significantly change between the 2 phases (Table 7) which would indicate that the elderly had contact with people and could turn to others for help when needed. The relationship between the elderly and others might have changed due to outmigration. However, the results show that the elderly can depend on others for support, an indication of community resilience.

Table 7

Number of Elderly that Respondents Had Contact With or Might Turn to them for Help In Both Phases

	Phase 1		Phase 2		t-test
	Mean	**(S.D.)**	**Mean**	**(S.D.)**	*p=0.05*
Number of people 65+ yrs you have contact with once/month	4.97	(6.33)	4.96	(2.86)	0.995
Number of people 65+ yrs who might turn to you for help	2.68	(2.53)	3.64	(2.41)	0.155

Demographic Characteristics of Main Informal Caregivers and Elderly Supporters

Research question 2: Is there a change in the demographic characteristics of informal caregivers during and after TAGS?

Table 8 provides a summary of the demographic characteristics for both main informal caregivers and elderly supporters grouped together. The results show that most informal caregivers were female and in their mid forties for both phases of the study. There was a significant increase in the percentage of informal caregivers employed during phase 2, especially for males. A significant decrease in unemployment for both males and females was also evident during phase 2. Individual income increased significantly during phase 2. Household income also increased however not significantly.

Table 8

Demographic Characteristics of All Informal Caregivers in Both Phases

	Phase 1			**Phase 2**			**t-test**	**Chi-Square**
	%	Mean	(S.D.)	%	Mean	(S.D.)	*p=0.05*	*p=0.05*
		n=123			*n=86*			df = 1
Age		42.24	(13.82)		44.67	(11.79)	0.144	-
Male	38.21			36.05			-	0.750
Age		42.21	(14.06)		47.13	(9.99)	0.058	
Female	61.79			63.95			-	0.750
Age		42.25	(13.77)		43.29	(12.57)	0.490	
Employment Status								
Employed	30.89			51.16			-	**0.003**
Male	19.15			51.61				**0.003**
Female	38.16			50.91				0.148
Unemployed	39.84			20.93			-	**0.004**
Male	55.32			32.26				**0.046**
Female	30.26			14.55				**0.037**
Retired	9.76			6.98			-	0.481
Keeping house	10.57			16.28			-	0.226
Student	8.94			4.65			-	0.237
*Income - Household		3.93	(1.53)		4.11	(1.69)	0.696	-
*Income - Individual		1.82	(0.88)		2.24	(1.38)	**0.006**	-

*Refer to Appendix A for income ranges.

Demographic characteristics of self identified main informal caregivers for both phases of the study are summarized in Table 9. The two groups were similar in terms of age and gender with only slight variations evident. However, significant differences were seen between the two phases in the area of employment with significantly more caregivers being employed in phase 2. Most caregivers in both phases were female in their mid forties.

Table 9

Demographic Characteristics of Main Informal Caregivers in Both Phases

	%	**Phase 1** Mean *n=34*	(S.D.)	%	**Phase 2** Mean *n=26*	(S.D.)	**t-test** *p=0.05*	**Chi-Square** *p=0.05* df = 1
Age		45.82	(16.53)		44.00	(11.46)	0.633	-
Male	26.47			26.92			-	0.969
Age		46.11	(14.04)		46.43	(8.52)	0.956	
Female	73.53			73.08			-	0.969
Age		45.72	(17.61)		43.11	(12.46)	0.585	
Employment Status								
Employed	23.53			50.00			-	**0.001**
Male	22.22			71.43				**0.049**
Female	24.00			63.16				**0.009**
Unemployed	26.47			15.38			-	0.511
Male	55.56			28.57				0.280
Female	16.00			15.79				0.985
Retired	23.53			19.23			-	**0.008**
Keeping house	20.59			15.38			-	0.606
Student	5.88						-	0.208
*Income - Household		3.53	(1.46)		3.38	(0.74)	0.778	-
*Income - Individual		1.87	(0.83)		1.67	(0.71)	0.554	-

*Refer to Appendix A for income ranges.

Results showed that elderly supporters had similar demographic characteristics to that of main informal caregivers. Most people were in their forties and female. It was noted that a higher percentage of males were involved with elderly support than actual informal caregiving. The only significant difference between phases was more elderly supporters were working during phase 2 (Table 10).

Table 10

Demographic Characteristics of Elderly Supporters in Both Phases

		Phase 1			**Phase 2**		**t-test**	**Chi-Square**
	%	Mean *n=109*	(S.D.)	%	Mean *n=75*	(S.D.)	*p=0.05*	*p=0.05* df = 1
Age		41.56	(13.00)		44.31	(12.26)	0.151	-
Male	40.00			36.00			-	0.583
Age		42.52	(14.19)		47.19	(10.01)	0.140	
Female	60.00			64.00			-	0.583
Age		40.92	(12.21)		42.69	(13.71)	0.463	
Employment Status								
Employed	31.82			48.00			-	**0.026**
Male	18.18			48.15				**0.007**
Female	40.91			47.92				0.457
Unemployed	41.82			24.00			-	**0.012**
Male	54.55			37.04				0.152
Female	33.33			16.67				**0.046**
Retired	7.27			6.67			-	0.874
Keeping house	10.00			16.00			-	0.225
Student	9.09			5.33			-	0.343
*Income - Household		3.95	(1.49)		4.12	(1.77)	0.626	-
*Income - Individual		1.81	(0.86)		2.23	(1.41)	0.054	-

*Refer to Appendix A for income ranges.

Psychosocial Health of Main Informal Caregivers and Elderly Supporters

Research question 3: Is there a change in the stress level of informal caregivers during and after TAGS?

Psychosocial health of main informal caregivers for both phases of the study is summarized in Table 11. The General Health Questionnaire (GHQ) measured somatic symptoms, anxiety/insomnia, social dysfunction, and depression. The GHQ indicated no significant difference in psychosocial health of main informal caregivers between the two phases. There was a general, but insignificant, decrease in stress levels in phase 2 with an insignificant decrease in somatic symptoms, social dysfunction, depression and the total results of the 4 sub-components during phase 2 while there was an insignificant increase in anxiety/insomnia (Table 11).

Table 11

Results of the General Health Questionnaire for Main Informal Caregivers during Both Phases of the Study

	Phase 1		**Phase 2**		**t-test**
	Mean	(S.D.)	Mean	(S.D.)	*p=0.05*
	n=34		*n=26*		
Somatic Symptoms	4.79	(3.49)	3.46	(2.75)	0.114
Anxiety/Insomnia	4.65	(4.39)	4.75	(4.62)	0.932
Social Dysfunction	7.09	(1.38)	6.72	(1.40)	0.318
Depression	1.94	(3.72)	0.96	(1.73)	0.220
Total GHQ	18.47	(11.06)	16.26	(7.94)	0.413

The General Health Questionnaire indicates no significant difference in psychosocial health between the two phases of elderly supporters. There was a general, but insignificant, decrease in stress levels in phase 2 with insignificant decreases in somatic symptoms, social dysfunction, depression and the total results of the 4 sub-components during phase 2 while there was an insignificant increase in anxiety/insomnia (Table 12).

Table 12

Results of General Health Questionnaire of Elderly Supporters during Both Phases of the Study

	Phase 1 **Mean S.D.** *n=109*		**Phase 2** **Mean S.D.** *n=75*		**t-test** *p=0.05*
Somatic Symptoms	4.17	(3.50)	3.44	(2.57)	0.123
Anxiety/Insomnia	3.81	(3.96)	4.15	(4.11)	0.573
Social Dysfunction	6.86	(1.81)	6.84	(2.00)	0.931
Depression	1.46	(3.02)	1.04	(2.06)	0.297
Total GHQ	16.30	(10.05)	15.58	(8.83)	0.622

Stress Level of Main Informal Caregivers and Elderly Supporters

Research Question 3: Is there a change in the stress level of informal caregivers during and after TAGS?

Stress level from all possible sources of stress of main informal caregivers was lower during phase 2 (Table 13) but only the relationship with children (*p*=0.027) was significantly lower during phase 2. As well, in both phases, the sources of most stress were employment status, financial situation, and the cod moratorium/TAGS.

Table 13

Sources of Stress of Main Informal Caregivers during Both Phases of the Study

1=Not at all Stressful and 7=Very Stressful.

Sources of Stress	**Phase 1** **Mean**	 **(S.D.)**	**Phase 2** **Mean**	 **(S.D.)**	**t-test** *p=0.05*
	n=34		*n=26*		
Cod moratorium/TAGS	4.70	(2.40)	4.08	(2.22)	0.433
Employment status	4.50	(2.26)	3.40	(1.88)	0.096
Financial situation	4.27	(2.21)	3.69	(1.83)	0.285
Relationship with spouse	2.56	(2.01)	1.50	(1.47)	0.053
Relationship with children	2.29	(1.86)	1.32	(0.78)	**0.027**
Relationship with parents	2.19	(1.86)	1.38	(1.02)	0.088
Relationship with employer	2.13	(1.81)	1.41	(1.18)	0.246
Relationship with co-workers	1.29	(0.76)	1.13	(0.52)	0.584

Survey participants were asked about stress levels and comparisons with stress levels from three years ago when TAGS had first ended. There was no significant change in stress between phases for main informal caregivers (Table 14).

Table 14

Main Informal Caregivers Stress Level (compared with 3 years before the study) and Current Stress Level for Both Phases

1= Much Less Stressful and 5= Much More Stressful

Stress levels	**Phase 1** **Mean**	 **(S.D.)**	**Phase 2** **Mean**	 **(S.D.)**	**t-test** *p=0.05*
	n=34		*n=26*		
Stress Level 3 years ago	3.53	(1.08)	3.15	(0.88)	0.154
Current Stress Level	3.65	(0.92)	3.50	(0.71)	0.501

Although stress about the cod moratorium/TAGS was highest on the list (Table 15), elderly supporters perceived significantly less stress from employment status (p=0.002) and not surprisingly, financial situation (p=0.025) during phase 2. This is understandable as more people were employed during phase 2. All other sources of stress were also lower, but not significantly lower during phase 2. The highest sources of stress for elderly supporters in both phases of the study were employment, the cod moratorium/TAGS, and not surprisingly financial situation. All of the latter decreased in phase 2 which supported findings on life satisfaction and stress level collected by using the GHQ.

Table 15

Sources of Stress of Elderly Supporters in Both Phases

1= Not at all Stressful and 7= Very Stressful

Sources of Stress	**Phase 1** **Mean**	**(S.D.)** *n=109*	**Phase 2** **Mean**	**(S.D.)** *n=75*	**t-test** *p=0.05*
Cod moratorium/TAGS	4.51	(2.34)	4.26	(2.29)	0.567
Employment status	4.42	(2.06)	3.25	(1.92)	**0.002**
Financial situation	4.17	(1.96)	3.50	(1.95)	**0.025**
Relationship with parents	2.01	(1.62)	1.78	(1.51)	0.364
Relationship with spouse	1.96	(1.44)	1.65	(1.34)	0.188
Relationship with children	1.80	(1.36)	1.48	(1.11)	0.156
Relationship with employer	1.71	(1.06)	1.61	(1.48)	0.752
Relationship with co-workers	1.36	(0.74)	1.26	(0.88)	0.582

Stress levels of elderly supporters significantly decreased during phase 2. When stress level was compared to that of 3 years before the interviews in both phases the present stress level was slightly higher that of three years before (Table 16).

Table 16

Perceived Stress Levels of Elderly Supporters Compared with 3 years Before the Interviews for Both Phases

1= Much Less Stressful and 5= Much More Stressful.

	Phase 1 **Mean (S.D.)** *n=109*	**Phase 2** **Mean (S.D.)** *n=75*	**t-test** *p=0.05*
Stress 3 Years ago	3.60 (1.09)	3.28 (0.85)	**0.034**
Current Stress Level	3.65 (0.88)	3.39 (0.80)	**0.044**

Life Satisfaction of Main Informal Caregivers and Elderly Supporters

Research question 4: Is there a change in the level of life satisfaction of informal caregivers during and after TAGS?

Main informal caregivers indicated a higher satisfaction with life during phase 2 of the study, with life in general (*p*=0.008), family life (*p*=0.024), and employment status (*p*=0.031) being all significantly higher (Table 17). All of the life satisfaction domains were higher during phase 2. However, again finances and employment status received the lowest scores.

Table 17

Life Satisfaction of Main Informal Caregivers for Both Phases

1= Very Dissatisfied and 7= Very Satisfied

Satisfaction with...	**Phase 1** **Mean (S.D.)** *n=34*	**Phase 2** **Mean (S.D.)** *n=26*	**t-test** *p=0.05*
Children	6.64 (0.73)	6.86 (0.47)	0.224
Friends	6.50 (0.66)	6.50 (0.71)	1.000
Spouse	6.48 (0.94)	6.75 (0.91)	0.330
Family life	6.09 (1.14)	6.65 (0.56)	**0.024**
Self	5.91 (1.19)	6.00 (0.89)	0.753
Health	5.50 (1.42)	5.54 (1.68)	0.924
Community	5.44 (1.52)	5.96 (1.28)	0.166
Way time spent	5.24 (1.30)	5.73 (1.12)	0.133
Life in general	5.21 (1.61)	6.19 (0.98)	**0.008**
Education	4.97 (1.68)	5.19 (1.44)	0.592
Finances	4.32 (1.66)	5.00 (1.30)	0.092
Employment status	3.65 (2.23)	5.10 (1.83)	**0.031**

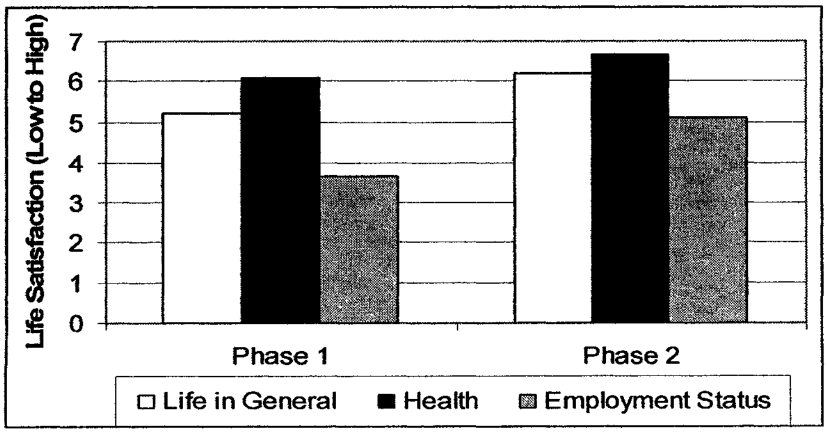


Figure 3. Significant phase differences in life satisfaction of main informal caregivers.

Life satisfaction also improved for elderly supporters during phase 2 (Fig 4), there was significant improvement for life in general (*p*=0.001), family life (*p*=0.005), community (*p*=0.009), and employment status (*p*=0.002). Table 18 indicates that almost all life satisfaction domains improved during phase 2. The high satisfaction with life in general, family, and community and low satisfaction with employment and income in both phases indicates the impact the fishery closure had on people's lives.

Table 18

Life Satisfaction of Elderly Supporters in Both Phases.

1= Very Dissatisfied 7= Very Satisfied

Satisfaction with...	**Phase 1** **Mean (S.D.)** *n=109*	**Phase 2** **Mean (S.D.)** *n=75*	**t-test** *p=0.05*
Children	6.74 (0.51)	6.80 (0.53)	0.564
Spouse	6.58 (0.69)	6.66 (0.96)	0.563
Friends	6.44 (0.78)	6.57 (0.70)	0.225
Family life	6.25 (1.05)	6.64 (0.71)	**0.005**
Self	6.10 (1.07)	6.20 (0.89)	0.495
Health	5.65 (1.52)	5.97 (1.26)	0.128
Way time spent	5.50 (1.29)	5.49 (1.23)	0.953
Community	5.42 (1.49)	5.99 (1.34)	**0.009**
Life in general	5.42 (1.43)	6.09 (1.18)	**0.001**
Education	5.26 (1.62)	5.51 (1.23)	0.266
Finances	4.48 (1.63)	4.87 (1.61)	0.116
Employment status	3.90 (2.09)	5.08 (1.92)	**0.002**

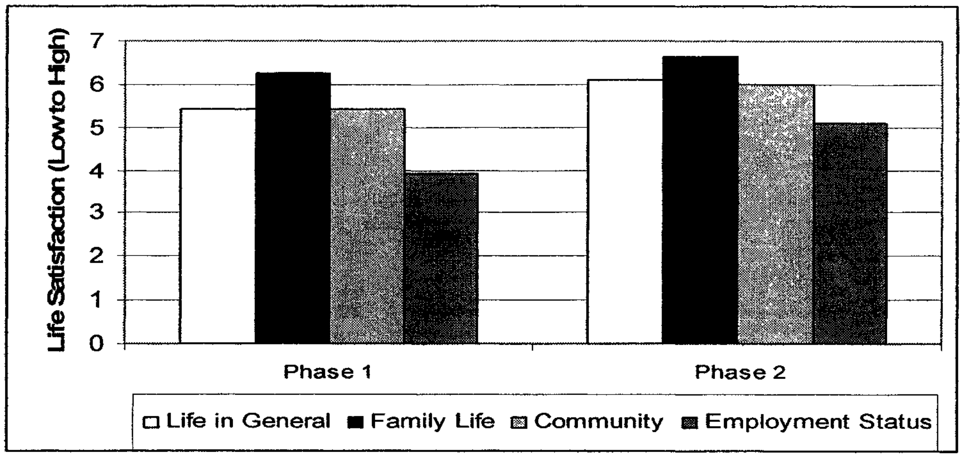


Figure 4. Significant phase differences in life satisfaction of elderly supporters.

Main informal caregivers were asked to self-evaluate their physical and mental health during the past 12 months. Mental health improved significantly during phase 2 while physical health also improved but not significantly (Table 19).

Table 19

Perceived Physical and Mental Health of Main Informal Caregivers during Both Phases

1= Very Unhealthy and 7= Very Healthy

	Phase 1 **Mean (S.D.)** *n=34*	**Phase 2** **Mean (S.D.)** *n=26*	**t-test** *p=0.05*
Physical health last 12 months	5.24 (1.37)	5.88 (1.27)	0.071
Mental health last 12 months	5.61 (1.41)	6.40 (0.87)	**0.016**

There was a significant improvement in the health of elderly supporters, with both physical (p=0.025) and mental (p=0.008) health improving during phase 2 (Table 20).

Table 20

Perceived Physical and Mental Health of Elderly Supporters in Both Phases

1= Very Unhealthy and 7= Very Healthy

	Phase 1 **Mean**	**(S.D.)**	**Phase 2** **Mean**	**(S.D.)**	**t-test** *p=0.05*
	n=109		*n=75*		
Physical health last 12 months	5.45	(1.51)	5.92	(1.13)	**0.025**
Mental health last 12 months	5.72	(1.37)	6.22	(1.01)	**0.008**

Main informal caregivers were asked specifically about the time demand and stress associated with caregiving. There was a non-significant decrease in both time and stress during phase 2 for the caregivers (Table 21).

Table 21

Caregiving Demands on Time and Stress of Main Informal Caregivers during Both Phases

1=Very Little Time and 3= Great Deal of Time

1= Not at all Stressful and 4= Very Stressful

Caregiving Demands	**Phase 1** **Mean**	**(S.D.)**	**Phase 2** **Mean**	**(S.D.)**	**t-test** *p=0.05*
	n=34		*n=26*		
Time	2.38	(0.70)	2.17	(0.78)	0.295
Stress	2.97	(0.90)	2.61	(0.84)	0.138

There was a general increase in the types of support given to the elderly during phase 2 (Fig 5) with emotional support (*p*<0.000), meal preparation (*p*=0.001) and banking (*p*=0.037) significantly increasing during phase 2. Most of the other types of support had a non-significant increase during phase 2 except transportation and personal care, which decreased non-significantly during phase 2 (Table 22).

Table 22

Types of Assistance Provided by Elderly Supporters in Both Phases (yes or no)

% Yes	**Phase 1** *n=109*	**Phase 2** *n=75*	**Chi - Square** *p=0.05* df = 1
Transportation for elderly	79.1	74.7	0.481
Emotional support for elderly	58.2	88.0	**0.000**
Grocery shopping for elderly	52.7	62.7	0.180
Banking for elderly	39.1	54.7	**0.037**
Meal preparation for elderly	36.4	61.3	**0.001**
Work around yard/garden for elderly	35.5	37.3	0.794
House cleaning for elderly	34.5	42.7	0.263
Home maintenance for elderly	29.1	29.3	0.972
Personal care for elderly	15.5	14.7	0.884
Financial assistance for elderly	4.5	6.7	0.531

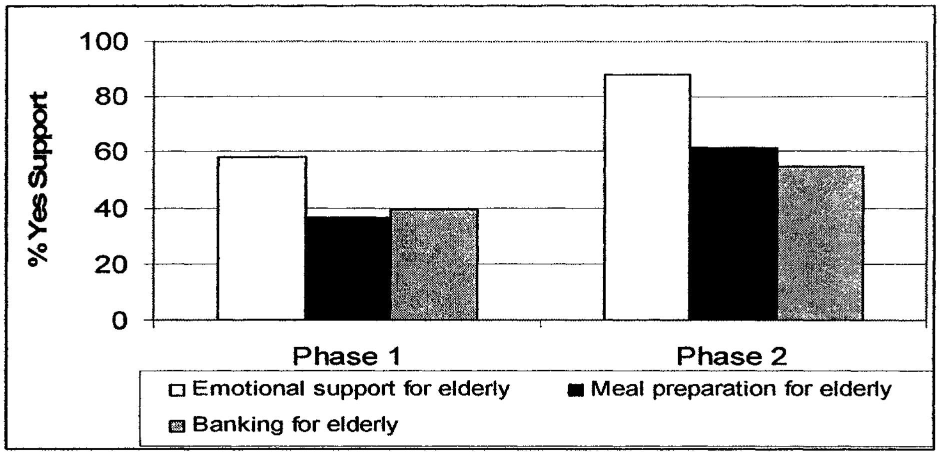


Figure 5: Types of support provided by elderly supporters that had a significant phase difference.

When asked if there had been any change in the past three years in assistance/caregiving activities results show that during phase 1, 41 of the 109 (37.6%) elderly supporters reported a change (increase), while 68 (62.4%) stated that assistance/caregiving stayed the same as usual. During phase 2, 20 of the 75 (26.7%) participants reported a change (increase), 55 (73.3%) reported that assistance/caregiving stayed the same as usual.

During phase 1, reasons for this change were reported as:

- Worsening medical condition
- Aging relatives
- Combining work and caring for relative
- Elderly relative moved in
- More time for caregiving

- Member of family moved away
- Death of one aging parent/relative

During phase 2, reasons for the change were reported as:

- Worsening medical condition
- Aging relatives
- Elderly relative moved in
- Member of family moved away
- Death of one aging parent/relative

Summary

In summary, analysis of the data for those who were caregivers of a person(s) with a long-term health problem as well as those who provided assistance to a relative age 65 or over during both phases of the study showed that a higher percentage of individuals were providing assistance to an elderly relative than providing direct care to a person(s) with a long-term health problem. For those who were providing care, there was no change in the care provided between phases. However, the proportion of elderly supporters decreased significantly during phase 2. For both phases as well as for both groups of informal caregivers, the demographic characteristics revealed that most caregivers were female and in their mid forties and that female caregivers provided more personal care and emotional support, while males performed more non-personal, maintenance type work. Employment also increased significantly for both groups during phase 2, and consequently unemployment decreased for both groups during phase 2. For both groups of caregivers, psychosocial health improved insignificantly in phase 2. Life satisfaction improved significantly in almost all domains for both groups of caregivers during phase 2 of the study. Stress from all measured sources of stress was insignificantly lower during phase 2, with the exception of relationship with children, which was significantly lower for main informal caregivers. Main informal caregivers also showed no significant change in stress between phases. Elderly supporters perceived significantly less stress from employment status and financial situation in phase 2. All other sources of stress decreased in phase 2 but not significantly. Stress levels of elderly supporters decreased significantly in phase 2 of the study.

Demographic characteristics for the total sample of the Bonavista headland showed similar results during both phases. People who remained in the area were significantly older during phase 2. Other significant results revealed that in phase 2 employment increased, unemployment decreased, individual income increased significantly, and significantly more individuals were keeping house.

Chapter 5

Discussion

The purpose of this study is to identify (in the Bonavista headland) if there was any change in informal caregiving during and after The Atlantic Groundfish Strategy (TAGS). Specifically, objectives include analyzing, during the two time periods, the percentage of informal caregivers, demographic characteristics of informal caregivers, and the stress level as well as the level of life satisfaction of informal caregivers. An overview of the demographic characteristics of the total sample during both phases of the study also provides insight into the demographic trends of the area. This chapter will discuss the findings in relation to previous research.

Demographic Characteristics

In this section the demographic characteristics will be discussed. Specifically, how the sample of this study compared to samples in other studies on a similar research topic will be explored. Next, the difference seen between the two time periods, namely during and after TAGS, relating to age, gender, employment status and income will be examined.

The percentage of those identifying themselves as main informal caregivers: those mainly responsible for caring for an adult(s) or child(ren) with a long term illness, physical or mental condition or health problem, is small for both phases of the study. During phase 1, during TAGS, of the 681 participants, 34 or 5% identify themselves as main informal caregivers. During phase 2, after TAGS, of the 671 participants, 26 or 3.87%, identify themselves as such. Results show that there is no significant difference in main informal caregiving between the two phases. However, there are more elderly supporters: those providing an elderly relative, i.e. someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care than main informal caregivers in both phases. Phase 1 has 109 or 16.15% who identify themselves as elderly supporters and phase 2 has 75 or 11.18% who so respond. Thus the percentage of elderly supporters is significantly lower during phase 2 when TAGS had ended. For both groups of informal caregivers employment also shows an increase during phase 2. However, only the percentage of elderly supporters significantly decreases during phase 2. This finding indicates that outmigration may have left those who remained to shoulder both paid work and informal caregiving. Further, during phase 2, some of the recipients of care are friends or clients, this might also be an indication of outmigration with so many people leaving the community there are fewer relatives left to care for those left behind. This is highlighted by Statistics Canada (2006b) who report that the population of Bonavista in 1996 was 4526 and in 2001, the population decreased to 4021, a change of -11.2%. Further, within the last five years the population changes of Elliston were -21.9, Catalina -16.2% and Bonavista -11%. The population of seniors age 65+ for the Clarenville-Bonavista region as of 2006 was 15.2% compared to 10.8% for the province as a whole.

The demographic characteristics of the population of this study during both phases shows that the majority of informal caregivers are female and in their mid 40's. This is congruent with findings of other researchers (Allen, 1994; Almberg et al., 1998; Cranswick, 2004; Fast et al., 2004; Ingersoll-Dayton et al., 1996; Neale et al., 1997). The employment status of informal caregivers significantly changes between the phases of the study with more caregivers being employed during phase 2. This reflects the findings of Pavalko and Artis (1997) who found that the provision of support to a family member or friend who is older or has a disability is disproportionately done by women in late midlife, which is the time when women's participation in the labor force is at its peak. However, continuing employment does not mean that women are forsaking care. Because of social pressure, gender expectations and lack of alternatives women tend to add to their responsibilities rather than alter them (Doty et al., 1998; Pavalko & Artis, 1997). Similarly, Bullock et al. (2003) found that employment status was not found to reduce caregiving hours. On the other hand, the findings of this study are not congruent with Boaz (1996) or Doty et al. (1998) who revealed that full-time employment reduces caregiving time significantly.

There are several possible explanations for the increase in employment of caregivers during phase 2. First, more individuals had to find employment since income supplementation from TAGS had ended. Secondly, outmigration may have played a role as those who were unemployed during phase 1 had left the area in search of employment while those who remained were possibly employed. As a result those who identify themselves as elderly supporters may have less time to devote to this type of activity, which may partly explain the decrease in the number of elderly supporters during phase 2. Other possible reasons for increased employment in phase 2 may be that many individuals have given up looking for a job, and may have not classified themselves as unemployed. Further, more participants declare themselves to be keeping house in phase

2 indicating that when employment is scarce women tend to assign themselves the housekeeping role instead of perceiving themselves as unemployed.

The demographic characteristics for the total sample reflect those of informal caregivers. However, age increases significantly for the total sample during phase 2. This may be partly explained by outmigration, as young people were leaving the community for work or school, as well many young families were leaving and these were the people of childbearing age, this had an effect on the average age of the population. This finding is supported by Statistics Canada (2006a) and by Lilley and Campbell (1999) who indicated that many young families left coastal communities in Atlantic Canada in search of employment thus contributing to the aging of the population. This helps explain the increase in employment and decrease in unemployment during phase 2, as there is less competition for available jobs in the area.

Stress

Stress is measured during both phases of the study using the General Health Questionnaire (GHQ); sources of stress are identified and stress levels are measured. As well, caregiving demands on time and stress are also measured. These variables are analyzed for both main informal caregivers and elderly supporters.

Results of the GHQ of main informal caregivers as well as elderly supporters indicates no significant difference in psychosocial health between the two phases; this may possibly be due to better employment status, hence higher income, resulting in increased life satisfaction in phase 2, as well as the fact that the sample of caregivers is predominantly female and living in rural Newfoundland.

Sources of stress for both groups of informal caregivers also decrease from phase

1. For main informal caregivers, stress related to relationship with children decreases significantly during phase 2. For elderly supporters, significant decreases are found with employment status and financial situation. These results may partially be due to the increase in employment during phase 2. As well, this reflects the general decrease in stress experienced by people in the area indicating that they have adapted to the cod moratorium. Those who are unemployed with high levels of stress have left the area. Further, results show high levels of satisfaction with life in general, with family, children and friends which possibly mitigate stress level reflecting the positive support available in rural communities.

Results measuring current stress levels and comparisons with stress levels from 3 years before the interviews reveal no significant changes in stress between phases for main informal caregivers. However, for elderly supporters, stress level compared to that from 3 years before the interviews shows a significant decrease for both between phases.

Caregiving demands on time and stress for main informal caregivers is measured. Results reveal that there is a non-significant decrease in both time and stress during phase 2. Perceived physical and mental health during the past 12 months of main informal caregivers as well as elderly supporters is measured. Results reveal that for main caregivers, mental health improves significantly during phase 2 while physical health also improves but the results are not significant. For elderly supporters both physical and mental health improves significantly during phase 2.

The findings from this study are congruent with those of Morgan et al. (2002) who identified that the majority of caregivers within rural contexts in Canada are female.

Similarly, Fast et al. (2004) found that in rural Canada daughters provide most informal care. Tanner Sanford and Townsend-Rocchiccioli (2004) reported that compared to the health status of the general population, rural caregivers, which were predominantly female, reported a statistically significant lower perceived health status than did the general population. Main informal caregivers in the present study show a non-significant improvement in physical health in phase 2, elderly supporters on the other hand show a significant improvement in physical health in phase 2. It is important to note however, that in phase 2 the number of elderly supporters decreases which may explain this finding. Similar to Tanner Sanford and Townsend- Rocchiccioli, Stewart et al. (2002) contend that the health status of rural women is the poorest of all women in Canada, as well; rural women have a lower life expectancy and are also known to access medical services less than the rest of the Canadian population. These findings remain unchanged over the last number of years as evidenced by previous research conducted by Burton, et al. (1997) who reported that women caregivers were less likely to engage in several preventative health behaviors than men. These researchers found that women were more likely to report not having enough time for rest and exercise, not being able to rest when sick, not being able to find time for doctors' appointments, and forgetting to take medications. Because women caregivers engage in fewer preventative health behaviors, they may be at a greater risk for physical as well as psychiatric morbidity. Similarly, Cuellar and Butts (1999) found that rural women reported a rapid deterioration in their own physical health related to symptoms of persistently interrupted sleep, chronic fatigue, irregular eating habits, and numerous muscle aches. These authors also contend that many rural women may become so immersed in the care they are providing to an elder, and ignore their own health problems, further contributing to their stress and ill health. Stress can result in chronically elevated hormone levels, chronic fatigue and poorer diets, factors that constrain the immune system and enhance women's susceptibility to a variety of acute and chronic illnesses (Bedard et al., 2004).

Several investigators who used general measures of psychiatric symptomatology found that women had higher levels of psychiatric symptoms. Using the GHQ, Collins and Jones (1997) found that a higher percentage of women caregivers than men caregivers reached the cutoff of 12 for psychiatric "caseness." Similarly, Young and Kahana (1989), in an older study, reported that women had higher levels of distress (Symptoms Checklist scores) than men. Using the General Symptom Index (GSI), Lutzsky and Knight (1994) showed that wives reported greater psychiatric symptomatology than husbands.

However, Schulz and Williamson (1991) in a longitudinal study examining gender differences in depression among dementia caregivers found that at Time 1, consistent with other studies, women reported more depressive symptoms than men. However, over a 2-year period, women's depression scores remained high and stable, whereas men's depression scores increased and became essentially equivalent to women's scores. In the present study, though it is cross-sectional, this finding could possibly help explain why the psychosocial health of caregivers remains unchanged between the two phases as the majority of the caregivers are women. The present study does not analyze the differences between male and female caregivers, thus future research exploring this area may help explain further this phenomenon in rural Newfoundland.

Chumbler et al., (2003) examined whether there were gender and kinship (spouse, child, more distant relative, friends) differences in caregiver burden. Results showed kinship, but not gender differences in caregiver burden. Adult children experienced more caregiver burden than more distant relatives and friends. Findings from this present study show that during phase 1 no one is providing care for a non-relative, however, during phase 2 almost half of the care recipients are friends. This may explain the decrease in stress level during phase 2 of the study as more care is provided to non-relatives. Further, these findings reinforce the notion that outmigration of young families leave the elderly to rely on friends and non-relatives for care and assistance.

Pinquart and Sorensen (2006) in their meta-analysis looked at whether large gender differences in psychosocial and physical health would be found in caregiver studies than in population-based studies not specific to caregiving. These researchers found that gender differences in caregiver health were larger than those observed in the general population. As well after investigating possible reasons for the difference concluded that the effect of gender remained statistically significant. Interestingly, these authors found that gender differences varied by caregiver age and year of publication. Stronger gender differences emerged in older samples and in older studies, thus Pinquart and Sorensen concluded that caregiving experiences of men and women have become more similar in recent cohorts.

However, this finding may not hold in rural settings. Past research has consistently found that caregiving is dominated by women (Cranswick, 2004). Kubik and Moore (2003) explain that this proportion of female caregivers is even greater among rural populations due to the expectation that women should and will assume traditional gender roles. Bowder (2002) reported that rural women might assume caregiving roles due to the belief that it is repayment to their parents for raising and caring for them as children. This is congruent with Cuellar and Butts (1999) who contend that the dominant cultural beliefs and attitudes within the rural context also shape the gendered positions of rural women. Within this context, women are seen as caregivers with the expectation that they will provide care for an elderly relative or ill spouse.

The present study, as with most others reported, is cross-sectional. As a result, the differential effects of caregiving on caregivers' physical and psychological health over time are not clear.

Life Satisfaction

Life satisfaction for both main informal caregivers and elderly supporters improves during phase 2 of the study. It is impossible to relate any change in caregiver life satisfaction to the caregiving experience itself in this study. However, the results may be explained by the fact that during phase 2 of the study employment status increases and when sources of stress are analyzed, stress related to employment status and financial situation both are significantly lower during phase 2. Further, improved levels of satisfaction with life in general, with family, children and friends possibly reflect the positive support available in rural communities.

Andren and Elmstahl (2005) found that even though caregiving is stressful satisfaction can be gained from the experience. These researchers revealed that the caregiver's gender, total burden and subjective health did not influence the degree of satisfaction, and the caregiver could feel both moderate burden and great satisfaction. However, Nolan (1996; 2001) has suggested that caregiving falls somewhere between the two extremes of burden and satisfaction for the majority of caregivers, and varies over time. Similarly Noonan and Tennstedt (1997) found that meaning in caregiving explained a significant portion of the differences in depression and self-esteem scores even after demographic and stressor variables had been controlled.

Haley, et al. (2003) found that high life satisfaction was associated with higher educational attainment and income. As well, better caregiver health was associated with higher ratings of life satisfaction. The present study findings are congruent with these researchers. During phase 2 of the study there is increased employment and income as well as increased satisfaction with employment. However, this study is descriptive in nature and no cause and effect conclusions can be drawn from the results.

There is a general increase in the types of support provided to elderly relatives during phase 2 of the study. Significant increases are noted in emotional support, meal preparation and banking. When asked to give reasons for any change in assistance/caregiving over the past 3 years, for both phases, most report an increase with reasons given such as worsening medical condition, aging parents, balancing work and caregiving, and a family member moving away. During the course of this study outmigration has a tremendous impact on the communities involved leaving those left behind responsible for providing care to ill and aging family and friends. As well, the bank, which serviced this area, closed, leaving many elderly people dependant on others to assist them with banking. Emotional support also increases during phase 2; this again may be partially explained by outmigration, as those left behind now provide support to elderly relatives. Also, due to increased aging, worsening medical conditions and the death of spouses a greater responsibility for caregiving and assistance is placed on informal caregivers.

It has been well documented that informal care provided in rural settings is more prevalent than in most urban areas (Keefe et al., 2004). This is in part explained by such factors as the growing population of people 65 years and older living in rural settings (Morgan et al., 2002) as well as the preference of many rural elders to remain within their communities (Lilley & Campbell, 1999; Morgan et al., 2004).

Congruent with findings from this study, challenges associated with providing care to an elder in a rural setting have been identified as transportation and distance from regionalized services as well as balancing other responsibilities such as families, jobs and household duties with caregiving (Armstrong et al., 2003). Similarly, Fast et al. (2004) found that female daughters provide 80-90% of the informal care for people aged 65 years and over. These authors also report that caregiving provided by women is more frequent and involves more traditional roles such as personal care, emotional support and housekeeping; where care provided by men is less frequent and associated with maintenance and repair of property.

With employment increasing during phase 2 of the study, the aging of care recipients as well as the worsening of medical conditions reflects findings of Health Canada (2002) who revealed that more than one in four caregivers indicated that their employment situation had been affected by caregiving responsibilities. Further, Statistics Canada (2002) reported on the employment consequences of giving informal care to persons aged 65 and over for caregivers aged 45 and over in Canada. Findings showed that caregiving resulted in reduced hours of work; changed work patterns; lost income; retired early; and quit job. As retirement income is based on the number of years spent in paid employment, caregiving has a long-term as well as immediate impact on the caregiver's financial well-being.

Summary

This present study reveals that there is no change in caregiving provided by main informal caregivers between phases even though employment increases during phase 2. This is congruent with the results of several studies that found that women caregivers tend to add to their responsibilities rather than alter them. In contrast, some studies reported that employment reduced caregiving hours significantly. The number of elderly supporters decreases significantly during phase 2 and almost half of the main informal caregivers are providing care to a non-relative. This may be explained by outmigration, leaving the elderly family members behind. The demographic characteristics of both phases show that the majority of informal caregivers are female in their mid forties; this is congruent with the findings of other researchers. Employment increases for both main informal caregivers as well as elderly supporters in phase 2 of the study. The psychosocial health of both main informal caregivers and elderly supporters shows no significant change between both phases of the study. Stress levels of main caregivers remain unchanged, however, stress levels of elderly supporters decrease significantly in phase 2, again this may be explained by the fact that employment increases and the number of elderly supporters decreases. The perceived physical and mental health as well as life satisfaction of main informal caregivers and elderly supporters also improves in phase 2 of this study. The improvement in employment and income as well as the fact that time has allowed the participants to incorporate the changes in their lives caused by the cod moratorium and subsequent end of TAGS may help explain this finding.

Chapter 6

Implications

Implications of study for Current Theory

Caregiving does not occur in isolation from one's social and experiential past or present, thus it must be considered within this context. The construct of caregiver characteristics was included to address the setting in which caregiving takes place, with emphasis on age, gender, income and employment, and rural residence. In other works these variables have emerged as key correlates of exposure to care related stressors, as well there is clear evidence in the literature to support an association between variables and the impact they have on the caregiver and thus on the outcomes of caregiving.

The present study findings provide a description of informal caregivers in the study area during both phases of the study. The cod moratorium led to massive outmigration. This changed employment status, as those who did not leave were employed. As a result there were less informal caregivers, but for those who provided care, the type of care changed and the level of care increased. Further, this study adds to the growing body of knowledge into the experiences of informal caregivers, more specifically rural informal caregivers. As a result the conceptual framework used to guide this study is supported by previously published research as well as by the findings from this study.

Implications for Nursing

Practice. The results of this cross-sectional study indicate several implications for rural informal caregivers and for nurses who practice within rural settings. It is important to discuss implications and recommendations for caregivers because healthy caregivers are able to provide better care for themselves and for care recipients in rural settings. Nursing implications and recommendations are also important because in many rural communities nurses may be the only or the most appropriate health care providers available (Leipert, 1999).

The findings from this study indicate informal caregivers need support in the form of education, building partnerships with formal care providers and with each other, and need enriched services and resources for informal caregivers, especially women, in rural settings. It has been suggested that the main reason rural informal caregivers refrain from utilizing formal support services are lack of information on availability of services and on the importance of using these services to prevent burnout (Morgan, et al., 2002). Thus, informal caregivers may benefit from learning about support services and resources that are available in their own or a neighboring rural setting, such as transportation services, in-home care and support, local respite care, and public policies and programs that support caregivers in rural settings. As well as providing direct support, these resources may provide ideas for rural communities about ways to develop enriched resources.

Rural caregivers may want to develop partnerships with formal care providers, such as nurses. Nurses within rural settings can offer caregivers information and assistance and can act as advocates for rural informal caregivers. For example, nurses and informal caregivers in rural and remote settings could lobby municipal, provincial and federal governments for enriched support resources in home care, health promotion and illness prevention, respite services and long- term care facilities.

It is essential for rural nurses to be able to identify and locate rural caregivers in order to assist them. Locating rural informal caregivers has been found to be a challenge because rural informal caregivers may not always obtain health care for themselves (Cuellar & Butts, 1999); rural caregivers may be identified through home-health visits with patients in the community, and by asking elderly patients in acute and long-term care settings about the support they receive from family and friends. In addition, nurses living in rural communities may recognize caregivers during various social and community events.

Nurses in rural settings must become aware of resources, such as transportation services, health promotion and illness prevention resources, in home care, long-term care and respite care that may be available to informal caregivers. Nurses can then assist informal caregivers in learning about and accessing available resources. Because of their knowledge of rural care providers, recipients and contexts, rural nurses must also act as leaders and advocates for needed services and resources in rural settings (Liepert, 1999). Rural nurses can become effective leaders and advocates with various informal groups and associations such as churches, community groups, special interest groups and women's groups as well as within formal nursing groups and associations. Rural nursing leadership and advocacy advance the development of policies, practices, and resources for rural caregivers and care recipients (Liepert, 1999; Thomlinson, et.al., 2004).

Nurses need to promote the education of informal caregivers and others about caregiving in rural communities. Through education, nurses are able to offer support to informal caregivers, assisting with the many decisions they are faced with and helping them to define boundaries and limits. Supporting informal caregivers' problem solving abilities helps to decrease the likelihood of burn out and enhances health and quality of life (Leipert, 1999).

Specifically, the results of this study will be useful to practicing nurses because they will increase nurses' understanding of how caregiving in the study communities has changed since the withdrawal of TAGS support. The finding that there were considerably more female informal caregivers than male caregivers in this study has important implications for professionals who serve caregivers. Women have been found to have more frequent, intensive, and affective involvement when in the caregiving role; thus, adequate assistance must be given to women caregivers to ensure that they are not strained beyond what is considered clinically healthy (Gallicchio, et al., 2002). Because of the potential health risks to caregivers associated with providing informal care, it is important that nurses be knowledgeable of whom the informal caregivers are in their communities so that education, interventions and programming can be specifically targeted. Appropriate resource allocation will improve the quality of care that is delivered to individuals, families and the community at large. While this study alone will not alter current public health interventions, it is a critical stepping-stone to developing more effective and appropriate care in affected communities.

In summary, caring for an ill or disabled individual constitutes a burden on informal caregivers. Assistance and support to caregivers would improve the quality of care and the lives of the ill and disabled, as well as the caregivers, ultimately benefiting the whole community. Nurses are in a unique position to provide such support, and therefore can take a leading role in lessening the potential negative consequences of informal caregiving.

Education. Nurses need to be active leaders in the recruitment and retention of nurses for rural practice. Nursing curriculums can foster recruitment and retention of nurses in rural areas by enriching rural theory and practice opportunities so that students gain an understanding of the rural context and how this affects rural health and nursing practice (Bushy & Leipert, 2005).

Rural nurses can act as preceptors and mentors to nursing students and they can support nurse colleagues who are new to the rural setting. These strategies may assist with recruiting nursing students to rural practices, as well as retaining nurses who currently practice in rural settings. As a result, the availability of appropriate healthcare services for rural informal caregivers and other rural residents may be enhanced.

Nursing students and practicing nurses must be knowledgeable of any change in caregiving that has occurred in communities affected by the cod moratorium since the withdrawal of TAGS. New nursing graduates, as beginning practitioners, will be expected to provide evidence-based care to individuals, families, and to the community as a whole. The findings of this study will provide support for nursing interventions aimed at informal caregivers. In addition to nursing students, nurse educators must be able to provide future nurses of rural Newfoundland and Labrador with current knowledge and skills that will equip them for delivering high quality health care.

Research. This study was carried out as part of a comprehensive study examining natural resource depletion and health and involved secondary analysis of an existing data set;

consequently it was not possible to examine all aspects of the complicated caregiving experience. The research community has a continuing role in supporting informal caregivers by obtaining other representative samples of caregivers from the entire spectrum of the caregiving-involvement continuum, conducting longitudinal research will allow an examination of the caregiving process as it evolves over time, taking into account the multidimensional nature of caregiving, and further exploring mechanisms to explain why certain caregiver characteristics, such as gender, are differentially associated with caregiving responsibilities.

A need identified in the literature is studies examining the biophysical sequale of caregiving. The central nervous system, the endocrine system, and the immune system all are part of the response to transient, repeated, and chronic stress; therefore physical health might be changed as a result of caregiver appraisal (Hansen-Grant, Pariante, Kalin, & Miller, 1998). More research exploring how caregivers appraise their experience and the impact of this appraisal on their health is warranted.

Nursing research must focus on women's issues and health within rural contexts with a specific emphasis on the informal caregiving roles of women. Qualitative nursing research in particular would assist with developing an understanding of rural women's caregiving experiences and needs. Increasing this knowledge base could prove beneficial by highlighting rural women caregivers' needs so they are evident to government and policy makers; therefore, potentially influencing future policy decisions to enhance rural health care.

Implications for Public Policy

The results of this study have broader policy implications. Several demographic trends point to an increased need for informal caregivers coupled with a decreased availability of individuals to provide care. Thus, more women, as well as men, will be called on to provide care in the future. With the aging population, outmigration, decreased fertility rates, and increased participation of women in the labor force the pool of available informal caregivers is becoming depleted.

Health care providers and policy makers need to seek the participation of rural caregivers, more specifically, women caregivers when planning programs, policies and research. Government at all levels and policy makers need to better appreciate and support women's caregiving in rural communities. The need for enriched services and resources for informal caregivers in rural settings is critical, and governments have a responsibility to attend to these rural needs.

Despite copious studies on caregiving burden and stress, informal caregivers continue to face a host of problems associated with lack of information, training, support, and respite services. Policy makers can address these systemic issues by funding broad range caregiver support programs as part of long-term care policies, thereby enabling capacity in the formal health care system.

Limitations

There are several limitations to this study that should be considered when interpreting the research findings. First, although samples in both studies were randomly selected, the participants involved in the *Natural Resources Depletion and Health* study are not necessarily the same as those involved in the *Eco Research – Health* Survey. This must be considered as a potential cause of any differences found in the data between the two time periods. Secondly, data in both studies were collected using self-report during face-to-face interviews. This presents the risk of social desirability bias, or the tendency of individuals to misrepresent their responses by giving answers that are congruent with what is deemed socially acceptable. Additionally, because local interviewers collected data, there is an increased likelihood of misrepresentation of responses because participants are not anonymous in their responses to questions. A third limitation is the small sample size of informal caregivers. A final limitation of the study is that no causal connection can be made between the time TAGS was in place and when TAGS ended to any change in informal caregiving. Although the purpose of the study was limited to comparing changes in informal caregiving during and after TAGS, an assumption underlying the study was that TAGS did impact the entire community as well as the entire province therefore it is logical to assume that informal caregivers were also impacted. However, changes observed could be due to other factors, such as, changes in demographics, cross-sectional design, programs, and policy.

Conclusion

A review of the literature revealed that informal caregiving is stressful and can have significant physical and psychological health consequences for the caregiver. Further, informal caregiving is dominated by women, and rural female informal caregivers have been shown to be at a greater risk for negative outcomes of caregiving. As noted in the literature, the total population of rural Newfoundland is decreasing and getting older. This places demands on those who provide care to this aging population. Specifically, this study revealed that informal caregiving in the Bonavista Headland is dominated by women and although limitations exist in the study design, this research raises important questions about the health and well being of rural informal caregivers as well as the care recipients. Furthermore, the results have direct implications for nursing practice and policy development and provide support for the need for a more specific strategic plan to care for the elderly in this province and provide support for informal caregivers.

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Appendix A

Survey Questionnaire

2. Starting with yourself, I would like to list the members of your household, their relationship to you, their age, sex and their usual occupation, i.e., what they usually do (**Names are not necessary**):

RELATIONSHIP	AGE	SEX	USUAL OCCUPATION
#1. Respondent			
#2.			
#3.			
#4.			
#5.			
#6.			
#7.			
#8.			

(If more than eight members list on reverse side)

employed part-time?	2 (GO TO b)
unemployed? (looking for a job)	3 (GO TO 5)
retired?	4 (GO TO 5)
keeping house	5 (GO TO 5)
a student	6 (GO TO 5)
retraining	7 (GO TO 5)
on disability	8
none of the above (specify)	9

b. Is this employment (**READ**):

permanent	1
seasonal	2
contractual	3

For the next items, please respond on a scale of "1" to " 7" where "1" is Very Dissatisfied and "7" is Very Satisfied and you can choose any number between "1" and "7".

How satisfied are you with:	very dissatisfied					very satisfied		DK	NA
a. your life in general?	1	2	3	4	5	6	7	8	9
b. your health?	1	2	3	4	5	6	7	8	9
c. your family life?	1	2	3	4	5	6	7	8	9
d. the amount of education you have?	1	2	3	4	5	6	7	8	9
e. your relationship with spouse or partner?	1	2	3	4	5	6	7	8	9
f. your relationship with your child(ren)?	1	2	3	4	5	6	7	8	9
g. your self (*self-esteem*)?	1	2	3	4	5	6	7	8	9
h. your relationship with friends?	1	2	3	4	5	6	7	8	9
i. your finances?	1	2	3	4	5	6	7	8	9
j. your community where you live?	1	2	3	4	5	6	7	8	9
k. the way you spend your time?	1	2	3	4	5	6	7	8	9
l. your employment status?	1	2	3	4	5	6	7	8	9
m. your retraining program? (specify program ________________)	1	2	3	4	5	6	7	8	9

8. (Please turn to page 2 of the answer booklet)

Now using a 7 point scale where "1" indicates "Very Unhealthy" and "7" indicates "Very Healthy" (and you can choose any number between "1" and "7"), please tell me:

a. How healthy have you felt physically in the past 12 months?

Very Unhealthy						Very Healthy	DK
1	2	3	4	5	6	7	8

b. How healthy have you felt mentally (emotionally) in the past 12 months?

Very Unhealthy						Very Healthy	DK
1	2	3	4	5	6	7	8

THE NEXT QUESTIONS ARE ABOUT STRESS IN YOUR LIFE.

12. Compared with three years ago would you say you life is **(READ)**:
    much more stressful 1
    somewhat more stressful 2
    about the same 3
    somewhat less stressful 4
    much less stressful 5

13. **a.** Would you describe your life as presently **(READ)**
    very stressful . . . . 1 **(GO TO b)**
    somewhat stressful . . . . 2 **(GO TO b)**
    not very stressful . . . . 3 **(GO TO 14)**
    not at all stressful . . . . 4 **(GO TO 14)**

14. **(Please turn to page 4 of the answer booklet).** The following are sources of stress in people's lives. Using a 7 point scale where "1" is not at all stressful and "7" is very stressful and you can choose any number between "1" and "7", tell me how you would rate each of the following as a source of stress for yourself:

	not at all stressful						very stressful	DK	NA
a. your employment status?	1	2	3	4	5	6	7	8	9
b. your financial situation?	1	2	3	4	5	6	7	8	9
c. your relationship with your spouse/ partner?	1	2	3	4	5	6	7	8	9
d. your relationship with your child(ren)?	1	2	3	4	5	6	7	8	9
e. your relationship with your parents?	1	2	3	4	5	6	7	8	9
f. the termination of TAGS?	1	2	3	4	5	6	7	8	9
g. your relationship with your employer?	1	2	3	4	5	6	7	8	9
h. your relationship with your co-workers?	1	2	3	4	5	6	7	8	9
i. your schoolwork/retraining? **(underline which one)**	1	2	3	4	5	6	7	8	9
j. other (specify) ______________	1	2	3	4	5	6	7	8	9

30. a. Are you mainly responsible for taking care of (READ).

an adult(s) with a long term illness, physical or mental condition or health problem .... 1 (GO TO b)
a child(ren) with a long term illness, physical or mental condition or health problem .... 2 (GO TO b)
no major responsibility for caregiving .... 3 (GO TO 31)

b. What is(are) the age(s) of these people and their relationship to you?

1. Age ____________ Relationship ________________

2. Age ____________ Relationship ________________

3. Age ____________ Relationship ________________

c. How much of your time would you say that this care requires? (READ)

a great deal of my time 1
a moderate amount of my time 2
very little of my time 3

d. Would you describe these caregiving demands as? (READ):

very stressful 1
somewhat stressful 2
not very stressful 3
not at all stressful 4

31. a. In total, how many relatives and friends over the age of 65 do you currently have contact with at least once a month?

Number of people? ____________(IF "ZERO" GO TO 32)

b. How many of these might turn to you for help?

Number of people? ____________

32. a. Are you currently providing an elderly relative, i.e., someone over 65 years old, with any financial assistance, emotional support, or other types of assistance such as help with household tasks, transportation, or personal care?

yes .... 1 (ASK b)
no .... 2 (Go to 33)

b. What types of help are you providing? **(READ)**

	Yes	No
financial assistance	1	2
emotional support	1	2
meal preparation	1	2
house cleaning	1	2
home maintenance	1	2
work around the yard/garden	1	2
transportation	1	2
grocery shopping	1	2
banking	1	2
personal care (e.g., bathing)	1	2
other, specify ____________________	1	2

c. Would you say overall, your assistance/caregiving activities in past three years have: **(READ)**

stayed the same as usual . . . . 1 **(GO TO 33)**
been more than usual . . . . 2 **(GO TO 32d)**
been less than usual . . . . 3 **(GO TO 32d)**
been much less than usual . . . . 4 **(GO TO 32d)**

d. What is the reason for the change?

____

____

THE NEXT QUESTIONS ARE ABOUT YOUR PAID EMPLOYMENT

36\. a. In total, how many years have you had paid employment? (including contractual or seasonal work) _____

b. In the last 5 years, how many times have you been unemployed (i.e., receiving EI and looking for work)? __________

c. In the last 5 years, how many times have you had to leave your job for maternity leave, care of your family, an injury or disability, or any other leave other than unemployment? ____________ (Circle type of leave)

38\. a. Have you had paid employment at any time during the past 12 months?

yes 1
no 2

55. a. What is range of the total income of all the members of your household for this past year before taxes and deductions?

Less than 10,000	1
10,001 - 20,000	2
20,001 - 30,000	3
30,001 - 40,000	4
40,001 - 50,000	5
50,001 - 60,000	6
60,001 - 80,000	7
80,001 - 100,000	8
Above 100,000	9

b. What is your own total individual income for this past year before taxes and deductions?

Less than 10,000	1
10,001 - 20,000	**2**
20,001 - 30,000	**3**
30,001 - 40,000	**4**
40,001 - 50,000	**5**
50,001 - 60,000	**6**
60,001 - 80,000	**7**
80,001 - 100,000	**8**
Above 100,000	**9**

Appendix B

The abbreviated General Health Questionnaire (GHQ-28)

pages simply by underlying the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

HAVE YOU RECENTLY:

1.	been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much Worse than usual
2.	been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
3.	been feeling rundown and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
4.	felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
5.	been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
7.	been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
8.	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
9.	had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
10.	been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
11.	been taking longer over the things you do?	Quicker than usual	Same as usual	Rather less than usual	Much less than usual
12.	felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
13.	been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
14.	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
15.	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
16.	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
17.	been able to to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
18.	been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
19.	been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
20.	found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
21.	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
22.	felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
23.	been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
24.	felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
25.	thoughts of the possibility that you might make away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
26.	found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
27.	found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
28.	found that the idea of taking your own life kept	Definitely not	I don't think so	Has crossed my mind	Definitely has