MARITIME CENTRE of EXCELLENCE for WOMEN'S HEALTH

Promoting social change through policy-based research in women's health

Caregivers' Support Needs:

Insights From The Experiences Of Women Providing Care In Rural Nova Scotia

A report presented to the Maritime Centre of Excellence by Joan Campbell, Gail Bruhm and Susan Lilley, November, 1998.

DALHOUSIE University

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Executive Summary

This research shifts the emphasis on family caregiving from "informal" to "primary" care, re-positioning caregivers at the centre rather than the periphery of homecare policy.

Insights gathered from a group of 46 family caregivers in rural Nova Scotia point to a pressing need for caregivers' contributions to be recognized. This group of caregivers feels that the formal care system does not value their role as primary caregivers; nor are their needs being met for appropriate information, training, and services to support their caring efforts. They need to be involved in shaping the policies, programs and treatment choices that affect them and those they care for.

A major thrust of Canadian policy on both long term care and health care reform is to shift care from institutions to communities. As seniors, the disabled, and the chronically ill receive less institutional care, more responsibility is transferred to their caregivers, who in most cases are family members. Yet, governments are redirecting only a fraction of savings from hospital closures and substitution with family care to services and programs that support care recipients and caregivers in the community.

This national shift to community-based care is not gender neutral. The label "family caregivers" has a strong gender bias, as women constitute the majority of caregivers. Two thirds (66%) of informal caregivers are women. This represents approximately 14% of all Canadian women over the age of 15. Of informal caregivers for people with dementia, 72% are women.

The needs of caregivers are likely to be greatest, and the resources fewest, in small communities and rural areas. This research project was designed to gather the views and experiences of rural caregivers. In this investigation, we asked family caregivers to share and analyse their stories about their caregiving experiences. The purpose of the research was to obtain practical knowledge about formal and informal services, programs and supports for caregivers. Another aim was to give voice to and validate caregivers' experiences. A multi-sectoral advisory committee guided the research process and will assist in disseminating results. The knowledge gained from the study is intended to inform policy makers and service providers, in an effort to increase support for caregivers.

The research method was qualitative and participatory. Story telling and structured dialogue were used to develop knowledge from personal experiences. This social process gave caregivers the opportunity to speak about their life experiences, to be heard, and to have their experiences validated by other caregivers.

Data were collected and analysed through four day-long workshops, each held in a different health region of Nova Scotia. Nine to 16 caregivers participated in each workshop. Caregivers analysed their individual and collective experiences through structured dialogue, identification of insights, grouping of insights into themes, and the creation of narrative statements about each theme. Content analysis was carried out by

the researchers, working with collected insights and narrative statements from all four workshops.

Caregivers who participated in the study were selected from the non- urban population of Nova Scotia. The 46 caregivers who participated included Blacks, Aboriginals, and Acadians. Although the workshops were open to male caregivers, all participants were women. Half of these were between the ages of 31 and 50, and roughly one third were between 51 and 65. A few participants were over 65, and one was under 31 years old.

The majority of these caregivers said they are on duty 24 hours a day, seven days a week. Fifteen percent (15%) told us they provide 24-hour care "with no relief," and 63% said they do so with "occasional relief". They provide care for people whose ages range from four years old to nearly one hundred. While some have been providing care for only a few months, others have been doing so for as long as 40 years. The average length of time spent providing care was 7.4 years.

Many of these caregivers have given up employment in order to provide care. Fewer than one quarter have paid employment. Close to half of those who are not currently employed reported that they had left a paying job or changed jobs previously because of caregiving responsibilities.

Four primary themes emerged from caregivers' collective insights into their stories:

- **a need to value the work of caregivers**
- **personal needs - surviving the "caregiving trap"**
- **practical needs - services and supports, financial assistance, information**
- **health care system issues and needs.**

Five additional themes were also significant, though not as important for these caregivers:

- **impacts of caregiving on other family members**
- **positive aspects of caregiving**
- **community responses to recipients of care**
- **transportation in rural Nova Scotia**
- **making caregivers' voices heard.**

Participants revealed frustration and dissatisfaction with the current support available from the government, service providers, families, and communities. They feel the government did not keep promises to provide comprehensive community care when closing local hospitals. According to these caregivers, the shift from institutional to community care in rural Nova Scotia must be accompanied by a commensurate transfer of resources so that services become comparable to the best available in urban centres.

These family caregivers spoke of the considerable burden associated with caregiving responsibilities. They said they need more support services, better matched with their actual needs and the needs of those they care for, as well as information on how they can provide care more effectively. Above all, they expressed a need for more respite, or relief time to care for themselves, so that they can maintain the health they need to carry out their caregiving role and contribute to their communities.

The caregivers who participated in this study have four critical messages for policy makers:

Recognize caregivers' contributions - The health care system neither acknowledges, nor appreciates their contribution as *primary* care providers. This lack of recognition results in frustration, and in inappropriate services and programs. Health policy must recognize caregivers as essential to the success of homecare programming.

Engage caregivers in the policy process - Although Nova Scotia' s Blueprint for Health System Reform (1995) recommended that informal caregivers be included in policy development and planning, caregivers feel they have not been included. They believe their knowledge, experience, and personal stake in the outcomes are essential ingredients for homecare policy development. They have many practical suggestions for supports and services, and they are prepared to make their voices heard. Improvements will result in policy and programs if caregivers are partners rather than adversaries in the decision-making process.

Provide support services and information - Caregivers are trapped in a downward spiral of stress and ill-health that impairs their effectiveness as caregivers. The service they most need is timely and appropriate respite care. They want services, information, and training for caregivers to be as available and up-to-date in rural Nova Scotia as anywhere in Canada.

Value caregivers' work - By reducing the need for costly institutional care through free labour, caregivers subsidize health reform and contribute substantially to the economy. Caregivers want compensation, through payment for their work, tax relief, pension benefits, or other means. Sustainability of a community based heath system that relies on family care depends upon providing compensation to family caregivers.

The information produced by this research goes well beyond documenting needs. The "story-dialogue" approach allowed for the capture of insights and knowledge which are grounded in the personal experiences of caregivers. The insights contained in the report will be of considerable value to everyone directly involved in homecare, and to anyone interested in enhancing the well-being of families in rural communities.

Table of Contents

Acknowledgments 3

Executive Summary 4

1. Summary of the Research Project 9

- 1.1 Goals and Objectives 9
- 1.2 Current Knowledge about Caregiver Issues 10
  - 1.2.1 Demographic and policy context 10
  - 1.2.2 Caregiver burden 11
  - 1.2.3 Caregiver policy issues 12
  - 1.2.4 Rural caregiver issues 12
- 1.3 Research Partnerships 13
- 1.4 Methodology 13
  - 1.4.1 Participant recruitment 13
  - 1.4.2 Workshop process 14
  - 1.4.3 Data analysis 15
- 1.5 Results 15
  - 1.5.1 Participants profile 15
  - 1.5.2 Caregivers' insights 18
    - 1.5.2.1 Practical needs of caregivers 18
    - 1.5.2.2 Surviving the "caregiving trap": caregivers' personal needs 21
    - 1.5.2.3 Health care system issues for caregivers 22
    - 1.5.2.4 Valuing caregivers' work 24
    - 1.5.2.5 Secondary themes 24

2. Research Implementation 25

- 2.1 Role of the Advisory Committee 25
- 2.2 Were Objectives Met? 26
  - 2.2.1 Generating practical knowledge 26
  - 2.2.2 Storytelling as community-based research approach 27
- 2.3 Evaluation 28

3. Dissemination/Knowledge Sharing 30

4.Implications for Maritime Centre of Excellence for Women's Health Mandates and Research Programs 31

- 4.1 Generating New Knowledge 31
- 4.2 Producing Information Reflecting Gender-Based Realities 32
- 4.3 Disseminating Information and Establishing Networks 32

4.4 Providing Policy Advice 32
4.5 Maritime Centre of Excellence for Women's Health Research Programs 33
4.6 Implications for Policy Making 33
  4.6.1 Recognizing caregivers' contributions 34
  4.6.2 Engage caregivers in the policy process 34
  4.6.3 Provide support services and information 34
  4.6.4 Value caregivers' work 35
4.7 Conclusion 35

Notes 35

References 36

Tables

Table 1: Profile of participants 16
Table 2: Caregiving circumstances of participants 17
Table 3: Evaluation questionnaire responses 29

Appendices

Appendix A Advisory Committee Membership 39
Appendix B Site Facilitators' Terms of Reference **
Appendix C Methodology 40
Appendix D Descriptive Information Questionnaire **
Appendix E Results 42
Appendix F Themes and Insights 44
Appendix G Practical Supports Suggested by Caregivers 49
Appendix H Definition of "Caregiving" 51
Appendix I Advisory Committee Minutes **
Appendix J Evaluation Questionnaires 52
Appendix K Instructions to Participants **
Appendix L Caregivers' Stories 54

***These appendices are not attached but may be obtained by request from the Maritime Centre of Excellence for Women's Health.*

Caregivers Support Needs: Insights from the Experiences of Women Providing Care in Rural Nova Scotia

1. Summary of the Research Project

1.1 Goals and Objectives

"Validating, listening to, understanding and building on women's individual and collective experience as caregivers -- experiences that have been traditionally hidden, devalued, and unacknowledged -- is the first step in breaking the silence that surrounds the issue of caregiving and is the basis for changing the prevailing pattern of care" (Hooyman & Gonyea, 1995, p346)

In this study, we asked women who are informal caregivers (Note 1) to share and analyse stories about their caregiving experiences in order to obtain practical knowledge about the formal and informal services, programs and relationships they require for support (i.e., specific, directed suggestions for assistance, services and programs). Our goal was to validate, listen to, understand and build on caregivers' experience as a step toward improving their quality of life.

The primary objective was to generate practical knowledge about gaps in existing caregiver supports -- from caregivers' perspectives. By providing caregivers the opportunity to tell and analyse their stories, we hoped to gather consensus about caregivers' needs from a range of women caregivers. They were selected to represent the non-urban population of Nova Scotia in terms of age, economic status, and ethnic background. The knowledge gained will be used to inform policy makers at all levels in an effort to build capacity for supporting caregivers.

A second objective was to demonstrate the value of sharing stories as a community-based research approach: "....if every women were to tell her story, there would be a sudden dramatic change in policy on aging." (Sommers & Shields, 1987, p. 170). We hope the same may be said for caregiving, that by sharing their stories in workshops, women may begin to feel empowered and "...by naming and identifying what was previously silent and invisible through collective social processes women ...(are) able to influence government and corporations to provide more resources in support of caring." (Hooyman & Gonyea, 1995). This research was not designed to mobilize caregivers; rather we intended to provide a process for validating caregivers' experience and by doing so, begin a process of empowerment.

1.2 Current Knowledge about Caregiver Issues

1.2.1 Demographic and policy context

A major thrust in current Canadian policy on long-term care and a cornerstone of health care reform driven by cost reduction is the shift to community based-care (Canadian Homecare Association, 1998; Havens, 1998; Rosenthal (1994). Policy statements concerning the restructuring of health services make reference to the "support", "responsibility", and "partnership" of families and volunteers that are required for successful substitution of services historically provided by hospitals and long-term care facilities. As Rosenthal has pointed out, such rhetoric overlooks the question of whether the shift is in the best interests of Canadian society. Instead, reference to partnership with families and volunteers presents the transfer of responsibility as necessary and inevitable, and attributes a supporting role, rather than ultimate responsibility, to governments.

The shift in responsibility for long-term care has not been accompanied by a commensurate transfer of resources (Chappell, 1998; Havens, 1998; Vowles, 1994), despite the changing demographic profile of those requiring care. As the size and proportion of the Canadian population made up of seniors is increasing, so too are average life expectancies. A significant segment of the population which needs institutional care -- frail elderly and those suffering from dementia -- is growing at a time when institutional beds are being reduced (Rosenthal, 1994). Meanwhile, those providing care are aging: currently, 50% of caregivers of dementia sufferers are 60 years old or older; one third are over 70 (Canadian Study on Health and Aging, 1994).

While seniors and their caregivers are the largest segment of the population affected by the shift to "community care", the reduction in institutional care services also affects those who are chronically ill, physically disabled, developmentally challenged and mentally ill. As these groups receive less institutional care due to loss of acute and long-term hospital beds, more responsibility is transferred to their caregivers, who, in most instances, are unpaid family members.

The wide and growing gap between the needs of "de-institutionalized" populations and their caregivers is not gender neutral; the label "family caregivers" masks a strong gender bias: women constitute the majority of family and volunteer caregivers. Two thirds (66%) of informal caregivers are women-- i.e., approximately 14% of all Canadian women over 15 (Statistics Canada, 1996). Of those caring for dementia suffers, 72% of informal caregivers are women.

Nova Scotia is a largely rural province, with 54% of seniors residing in rural areas (N.S. Caregiver Support Committee, 1995). As well, Nova Scotia has the highest disability rates of any province in Canada. In a recent population health survey, 10% of Nova Scotia women -- the majority between the ages of 35 and 64 -- reported providing care on a regular basis to elderly or disabled family members (N.S. Department of Health, 1995).

1.2.2 Caregiver burden

Canadian caregivers report deterioration in health (20%) and sleep disturbances (25%) among a variety of impacts of caregiving on their lives (Statistics Canada, 1996). Caregivers of dementia sufferers are more likely to suffer chronic health problems and depression than those caring for non-dementia sufferers, and depression increases with the age of caregiver (Canadian Study of Health and Aging, 1994). In Nova Scotia, 53% of women who are informal caregivers report some stress, while 13% indicate they are often or always stressed (N.S. Department of Health, 1995).

The concept of caregiver burden (Hooyman and Gonyea, 1997) encompasses objective stress (e.g., loss of income) as well as subjective experience (e.g., emotional strain). Caregivers may experience burden from: caregiver characteristics (e.g. gender, age, health status) care recipients' symptomatic behaviors associated with illness/disability (e.g., hostility, wandering, incontinence); economic pressures (e.g., loss of income, cost of equipment and care); economic consequences of caregiving (e.g., loss of opportunities for higher paid positions, pension accumulation); employment restrictions (e.g., job loss, reduction in paid hours worked); restrictions on leisure and social relationships (e.g., family conflict, vacations) (Hooyman and Gonyea, 1995; Keefe & Medjuck, 1997).

In their review of the literature, Hooyman and Gonyea conclude that the contradictions and inconsistencies in the research literature regarding determinants of caregiver burden may reflect true differences in caregiving experience as much as lack of comparability between studies . They point out that to understand the gendered nature of caregiving and the stress process, we must recognize the distinct roles, resources and values that women and men bring to the caregiving experience. Subjective, personal meaning ascribed to stress, and attributes such as gender, race and class (which present different structural barriers and opportunities for caregivers) may be the best predictors of caregiver burden.

1.2.3 Caregiver policy issues

The Nova Scotia health reform strategy explicitly recognizes that "...most informal caregivers are women, many of whom have other work and family responsibilities.." and expresses an intention. "...to incorporate and support the key role played by informal caregivers and volunteers into the policy formulation and planning initiatives of the reform process, particularly in the areas of home care, respite care..." (N. S. Department of Health, 1995, p. 19). In a recent program description of Home Care Nova Scotia, however, which profiles services, challenges and initiatives, there is no mention of caregivers. It seems clear that involvement of and support to caregivers has been subordinated to the pursuit of other program goals: cost reduction through substitution of services; maintaining clients in less costly locations, i.e., home environments; and prevention and monitoring services. (Canadian Home Care Association, 1998)

A recent study of caregiver needs in Atlantic Canada conducted focus groups with providers of services to caregivers (Nova Scotia Centre on Aging, 1998). From the focus groups, a consensus developed that "..provincial climates for offering caregiver supports were ones of rigid, often fragmented systems which were not 'user friendly' ." (p. 38) An array of needed services and supports were identified, from emotional and social supports to information, finacial support, respite nursing, home support, diagnostic services and loans of personal aides and equipment. Care providers identified three priority issues for caregivers: need for effective communication among service providers, need for coordination of existing supports, and need for advocates to assist caregivers in navigating the system and accessing appropriate supports.

Important policy-implementation gaps regarding caregivers' needs have been identified, especially with respect to paying caregivers for their work and offering employment flexibility. Loss of institutional care options and absence of sufficient formal services for community-based care are gaps created by health reform that have significant impacts on caregivers as well as those they care for (Rosenthal, 1994). Havens (1998) suggests that the major concerns for caregiver policy are standardizing terminology, definitions, standards and policies among Canadian jurisdictions to ensure comparability of caregiver services, preventing caregiver "burnout", and addressing women's role as informal and formal caregivers. In Havens' view, particular attention needs to be paid to issues of women who are juggling employment and caregiving responsibilities.

Finally, given differences between and among women and men in employment patterns, time use, caring capacities, financial status, etc., the importance of applying gender lens methods to caregiver issues to ensure equitable and effective policies and programs must not be underestimated (Maritime Centre of Excellence for Women's Health, 1998).

1.2.4 Rural caregiver issues

A variety of indicators suggest that rural Canada is under stress and undergoing transformations in demographics, social and economic status and quality of life. In general, rural Canadians have less education, lower average incomes and higher rates of unemployment and illiteracy, and receive a larger share of federal transfer payments than their urban counterparts due to the magnitude of the demand for social assistance in rural communities (Bollman and Biggs, 1992).

Available data suggest that rural communities are communities at risk (Bavington, 1994). Rates of long term disability and chronic illness are higher in rural communities than in cities (Wilkins, 1992). This is partially explained by the high proportion of elderly in the make-up of rural populations: nearly one third of Canadians over 65 lived in rural areas in 1991 (CMHC, 1991; Hendryx, 1993). The disproportionately high numbers of the elderly and disabled living in rural communities places special demands on declining health services and on family caregivers.

In the Nova Scotia Centre for Aging (1998) focus group interviews, caregiver service providers indicated that caregiver services and supports are unevenly distributed across the Atlantic region, with higher concentrations of services in urban centres. Focus group informants felt that rural caregivers tend to rely more on informal networks and supports, in part out of a sense of self-reliance, a strongly held rural value, but also out of necessity, due to lack of services.

The needs of caregivers for support are likely to be greatest and the resources for them fewest in small communities and rural areas. Resources for caregivers are minimal in rural areas of Nova Scotia (Keefe and Fancey 1997). Since patchwork homecare services cannot be relied upon for comprehensive coverage in remote rural areas, increased burden for caregivers is the likely result. Due to prevailing conservatism and traditional views of gender roles, women who are caregivers in rural areas are likely to experience even greater burdens than those in urban areas (Bushy, 1993).

1.3 Research Partnerships

We undertook this research in consultation with a multidisciplinary, multi-sectoral group of stakeholders in the caregiving issue which oversaw and guided the research process. This Advisory Committee consisted of representatives from community organizations, universities, and government, most of whom are participants in an existing multisectoral network, the Nova Scotia Caregiver Support Committee.

The role of the Advisory Committee was to guide the project and provide stakeholder representation throughout the research process. They were chosen as research partners for their long-standing involvement in caregiver issues, their influence and ability to effect change, and their access to a broad spectrum of clients, resource providers and policy makers at whom the results of this research will be directed (see Appendix A for committee composition).

1.4 Methodology

1.4.1 Participant recruitment

Workshop sites were selected in each of the four health regions in Nova Scotia, in consultation with the Advisory Committee, to represent as broadly as possible, the caregiving population of Nova Scotia. Sites were Digby (Western Region), Sheet Harbour (Central Region), New Glasgow (Northern Region) and St. Peter's (Eastern Region).

Efforts were made to include black and aboriginal Nova Scotians, low and middle income, employed and unemployed women, and women from culturally distinct regions of the province. We had hoped to include immigrant women, but the limited presence of immigrants outside of urban centres made this impractical. We hired four local site facilitators to assist with contacting potential participants, to arrange meeting space, and to assist with the workshops in each of the regions. **S**ite facilitators were recruited by Gail Bruhm, based on recommendations from Advisory Committee members and others in service networks and local communities. They were chosen for interest and/or experience with caregiving issues in their own communities as well as familiarity with the range of local social services. As a condition of hiring, site facilitators were asked to give a written undertaking to respect participants' confidentiality. Their terms of reference are presented in Appendix B.

Because there are no established caregiver networks, potential participants were identified by site facilitators though contacts with local service providers/organizations likely to be involved with informal caregivers, such as family physicians, and local community organizations, including local Home Care Nova Scotia and VON offices. For further details of the recruitment process, see Appendix C.

Training in the story dialogue methodology was provided to site facilitators, the research team and interested members of the Advisory Committee by Susan Lilley, who is experienced in the story dialogue methodology (see Note 2). Training included methodological and ethical considerations, including the importance of maintaining confidentiality with respect to all aspects of participants' circumstances and participation.

Out-of-pocket expenses were covered for participants, including gas for automobile travel and respite care.

1.4.2 Workshop process

"There is a seed that is somehow planted for another generation when we listen to wise, wonderful and witty stories...A great sense of stress and fears are lifted for both the caregiver and the care receiver." (Note 3)

The research method is a qualitative, participatory approach developed by Labonte and Feather (1995, 1996; Lilley, 1996) which uses narrative storytelling and structured dialogue to convey experience and develop knowledge. The *story-dialogue method* was developed specifically for application in the health promotion field, but as a tool for deriving meaning from common experiences, the originators have suggested that it can be applied in other contexts. The approach allows each participant to tell a personal story relating to a particular theme to others in a small group. Participants gather insights from each others stories through discussion, guided by questions about *what* happened, *why* it happened, and given that it happened, *so what ?* and *now what?* Then, insights from several groups are pooled and categorized, and participants develop narrative statements for each category.. These narrative statements are, in effect, recommendations in the voice of the participants.

We chose the story-dialogue approach because it provided a model of a collective social process that would give caregivers the opportunity to speak about their life experiences, to be listened to and have their experiences validated. At the same time, the structured reflection ensured that generalizations were made from discussion of individual stories.

The research data gathering consisted of four day-long workshops in sites around Nova Scotia, with 9 to 16 participants in each workshop. Refreshments and lunch were provided. For further details of the workshop process, including recording, see Appendix C.

1.4.2 Data analysis

The first step in organizing the data was to transcribe the handwritten text of the narrative statements. Text was analysed by the first author (Joan Campbell) in an iterative process of conceptualization and comparison for ideas, patterns and concepts reflecting the reality of caregivers' lives as told to us. Despite differences in these caregivers' life situations (discussed below) there were many commonalties in the meanings ascribed to their experiences. Nine emergent themes were identified (see Appendix F), of which four are deemed to be primary themes: the weight of consensus across four workshops and a range of caregivers compels attention to these priorities.

To establish a degree of interpretive validity, we had the full research team and the Advisory Committee review the array of emergent themes (With two exceptions, all had observed at least one of the workshops.). If, in the view of this diverse group of stakeholders, the themes derived through the analytic process captured caregivers experiences as told to us, then as researchers we could feel reasonably confident that we were illuminating lay knowledge rather than reflecting our own interpretations (Popay, Rogers & Williams, 1998). There was complete agreement with the categorization, labeling and prioritizing of themes as presented.

Finally, a draft of the Executive Summary of the report was sent to participants and site facilitators for review, with requests for comments if they felt the summary did not reflect their views. Of four caregivers and one site facilitator who responded, all expressed strong agreement with the results as presented in the Executive Summary. We believe their concurrence is a key validation of this research.

1.5 Results

1.5.1 Participants profile

Four site facilitators contacted a total of 121 individuals to participate in the workshops. Each site facilitator used her own local network to identify potential participants. A variety of local organizations were approached as sources of caregiver contacts, including: VON, women's centres, local offices of Home Care Nova Scotia, Mi'kmaq health office, band office, a public health nurse, pharmacists, caregiver support group, community social workers, employment resource centre, family resource centre, a field worker for the N.S. Advisory Council on the Status of Women, local hospice workers, band councils, Black Employment Partnership, and local clinics.

Among those approached, about half -- 65 individuals -- agreed to participate. A total of 46 persons (70.7%) actually participated in the four workshops. Reasons given for not participating included: don't have time, can't leave the person being cared for, can't take time from job, feel uncomfortable about the idea, don't have anything to contribute, don't have transportation, too close to death of care receiver, cannot sit for long due to arthritis, and have other commitments.

To get a picture of the caregiving situations of those who participated, we asked each person to complete a 19 item, descriptive "Information Questionnaire" at the workshop (see Appendix D). All participants completed the questionnaire, which posed structured questions about who was being cared for, how long the caregiver had been providing care, how much time was spent caring, whether the person being cared for lived with the caregiver, whether the caregiver was/had been employed, and whether the household ever ran out of money for food. We also asked open ended questions about what help caregivers received and who else lived with them.

Table 1 presents descriptive details. Of the 46 caregivers who participated, Blacks, Aboriginals, and Acadians were represented. All participants were women. Half of the participants were between the ages of 31 and 50. Roughly one third were between 51 and 65. Fewer than 10% were over 65, and only one individual was under 31 years of age. One of the biggest sacrifices many caregivers make is employment. In this group, fewer than one quarter have paid employment. Those who are employed work an average of 22.2 hours per week. Of those who do not have paid employment, 50% reported leaving or changing a paying job because of caregiving responsibilities.

Table 1: Profile of participants (N=46)

Age:		**Sex:**	
under 30	2.2%	**Female**	100%
31-50	50.0%	**Male**	0%
51-65	34.8%		
over 65	10.0%		
Cultural background:			
Aboriginal	4.3%		
Acadian	6.6%		
Black	13.0%		
Other	76.1%		
Employed:	23.9%	**Average hours of paid employment:**	22.2 hr./wk.

If unemployed (n=34) -- left/changed employment because of caregiving:	50.0%
Household runs out of money to buy food	15.2%

Details of the caregiving situations are presented in Table 2. The majority of these caregivers are on duty 24/hr. day: 15.2% told us they provide care 24 hr./day "with no relief", while 63% get "occasional relief" from being on duty 24 hr/day. A handful are called upon to provide 24-hr. care a few days at a time (e.g., weekends), a few hours each day, or a few hours each month. Their caregiving responsibilities are not limited to caring for seniors. The ages of those being cared for by this group cover the life span, from children and youth to nearly 100 years old.

Table 2: Caregiving circumstances of research participants (N=46)

Person receiving care		**Age of person receiving care**	
spouse	19.5%	18 years old or under	12.7%
parent	31.7%	19-65	19.1%
disabled/ill child under 16	7.3%	66-80	31.9%
disabled/ill child over 16	14.6%	81-100	34.0%
brother/sister	2.4%		
other relative (e.g., grandparent)	17.0%		
neighbour	2.4%		
friend who is not a neighbour	4.9%		

Amount of time spent caregiving (n=44)		**Years spent caregiving**	
24 hr./day year round, without relief	15.5%	0-2 years	30.4%
24 hr./day year round, with occasional relief	64.4%	3-6	26.0%
24 hr./day, a few days at a time	6.7%	7-15	30.4%
a few hours each day	8.9%	16-40	13.0%
a few hours each month	4.4%		

Caregiver caring for more than one individual	12.0%	**Sole caregiver for person receiving care**	69.6%
Care provided in caregiver's home	69.6%	**Caregiver relocated to home of person receiving care**	13.0%
Average length of time to reach care receiver not residing with caregiver (n=9)	16.9 minutes		

Caring for someone is a long-term proposition. As a group these caregivers have been providing care for periods ranging from a few months up to 40 years in one case. The average length of time spent providing care is 7.4 years.

Appendix E discusses the results in further detail.

1.5.2 Caregivers' insights

Nine themes emerged from analysis of caregivers' collective insights into their stories (see Appendix F). We identified four of these themes as primary issues for caregivers:

- **practical needs - services and supports, information, financial assistance**
- **caregivers' personal needs - surviving the "caregiving trap"**
- **health care system issues for caregivers**
- **need to value caregivers' work**

Regardless of individuals' circumstances and personal resources, the subjective meaning associated with their caregiving experiences -- as embodied in these common threads -- was widely shared and deeply felt.

1.5.2.1 Practical needs of caregivers

"There are special, individual needs, different from the needs of the average family, you don't even know where to turn for help."

Caregivers want to be appreciated and have their work valued; lack of validation contributes to their caregiving burden. They experience many other pressing needs, however, that are highly practical. To help them become more effective caregivers, and to relieve some of the burden they experience, these caregivers expressed practical needs in several areas: information and training programs, peer support, financial assistance and a range of supports and services in their local communities. These are discussed under three sub-themes below. A list of suggestions from caregivers for needed services and information is found in Appendix G.

Practical needs: Supports and services

"At the present time, caregivers involved with loved ones suffering any type of illness are in a very stressful position. Our communities lack in financial and emotional support systems."

This group of caregivers acknowledges that it is not easy for caregivers to ask for assistance: ***"Caregivers won't ask for help , so friends and neighbours should just offer help....asking 'how are you?' instead of 'how is your mother'? could help."*** Thus, it is not surprising that they say they are frequently disappointed with the level of support they receive from families and their communities. They believe the answer is to raise public awareness: "***Since we get little public empathy and understanding of the caregiver role, we feel more education needs to be directed towards whole communities."***

They believe ***"Caregiving is a community issue."*** Because their work benefits their families and communities they feel they should receive more in the way of practical assistance and support, for instance ***"...there should be programs for caregivers in the community...",*** and "***..a network of volunteers to deal with domestic chores...".*** They want a range of services, from classes on "how to be a caregiver", to seniors day-care, exercise and recreational facilities, retreat centres, caregiving workshops for families, community clinics, professional counseling, respite, a 1-800 number for medical, legal and financial advice, etc.

In addition to needing services to improve their lives, caregivers told us that the antidote to the feelings of isolation that most of them experience is to meet regularly with people who understand what it means to be a caregiver, i.e., other caregivers. Our own experience with caregivers in the four workshops reinforces this notion. Repeatedly, we heard comments like the following: ***"Talking about [our] situations with other caregivers who have similar experiences is beneficial" ,*** and ***"Caregivers support groups are a much needed community asset. Here, caregivers can, under confidentiality, share humorous stories and know there are others that share the same fears"***

It is noteworthy that in all the discussions about services and supports needed to improve their lives as caregivers, these women rarely mentioned current services and supports that they are satisfied with. When they spoke about who was helping them, the references were usually to family members or friends (e.g., spouse or sibling relieving a caregiver for some period of time). Mention of non-government service providers was notably absent, except in discussions of what is not working. When health care providers -- doctors, nurses, social workers -- were mentioned at all, it was in the context of the need for coordination among them and for greater recognition on the part of professionals of the primacy of the caregiver role.

Caregivers are in a position to know which community organizations and service providers in their local communities are effective and reliable at meeting their needs. If partnerships between governments, non-profit organizations, and/or the private sector are going to be established for providing services to caregivers, then further work needs to be done to identify local community partners who have the confidence of caregivers.

Practical needs: Information and training

"Knowledge is power. We need to engage in learning all we can regarding a person's illness and home life conditions so we can better meet their needs."

One of the greatest gaps in support for caregivers seems to be in information resources. These caregivers have a great need for readily accessible, detailed, up-to-date information on services and resources available to them and those they care for, as well as training and advice on how to provide care for a range of conditions.

Regardless of which region of the province they live, caregivers tell us they don't know where to turn for information. They report that often they receive conflicting or out-of-date information from government agencies, sometimes, depending on whether they deal with local officials or officials based in Halifax. They want information to be up-to-date and the professionals they deal with to be knowledgeable and consistent in their advice.

As well, they want training so they may become better care providers: ***"Just as there are parenting classes there should be caregivers classes which would enable the caregiver the confidence to do their best",*** suggesting that educational programs such as the "Care for the Caregiver" project (Fancey, 1997) which provided educational workshops for Nova Scotia caregivers, should be an integral part of caregiver support policies.

They want easily accessible sources of information in each community, not only about the full range of resources and supports available to them, but also, they want ready access to specific illness/disability information: ***"We need information and material to be make available in public places, libraries, clinics, and the internet....a directory of information and a 1-800 number needs to be created, for counseling, legal, breaking-through-red-tape, and medical information."***

"If there were a community resource person who is available to act as a liaison between caregivers and the resources available to them within the community, it could markedly reduce the stress, therefore making us better caregivers." The need for a resource person to help caregivers navigate through the service system has been identified not only by caregivers, but also by service providers, in the N.S. Centre for Aging (1998) study. A possible model may be the patient advocate position which exists in many hospitals.

Practical needs: Financial assistance

"When applying income eligibility to requests for financial assistance, several things should be considered, not just actual income, but other costs and expenses the special needs families incur, [for instance] medication costs, special foods, transportation and medical supplies [such as] diapers, creams, lotions, colostomy bags, insulin, wheelchairs, commode chairs, bars for bathrooms, etc."

These caregivers told us there is a considerable financial burden associated with the caregiving role. Some of them (15%) regularly run out of money to buy food. Basic income security is an issue for them: because of time spent providing care, most cannot engage in paid employment to support themselves. When they do work, they are usually constrained by their caregiving responsibilities to low-paying, part-time and/or casual employment. For the 23.9% of this group who are employed, the mean number of hours worked per week is 22.2 [Forty-two of out of the 46 caregivers (91%) are of "employable" age, i.e., under 65 (see Note 4)].

“The solution to alleviate the burden on caregivers who stay home would be to remunerate the caregiver or give an income tax credit each year (provincial and federal assistance)”. These caregivers want to be compensated fairly for the work they do. They are aware that their labour is subsidizing health care restructuring, and that in some jurisdictions and in other countries (e.g., Australia) , caregivers are paid for their labour. As Keefe & Fancey (1997) point out, compensation is not equivalent to payment, or actual reimbursement for labour. Nevertheless, even minimal compensation "...refutes the invisibility of caregivers labour." (1997, p. 274).

In addition to income deficiencies, caregiving frequently is associated with special costs of providing care, e.g., supplies, equipment, medications, home renovations, transportation, non-insured homemaker services and nursing services, etc. These costs of caregiving need to be incorporated into eligibility criteria for government assistance to families where care is being provided (e.g., In-Home Support) and for income support to caregivers (e.g., Home Life Support). Currently in Nova Scotia, only caregivers whose family income is at or near the poverty line are eligible for these particular programs, which are offered only in certain municipalities.

Based on their study of 136 caregivers receiving financial compensation or home help services in Nova Scotia, Keefe and Fancey recommend removing stringent eligibility criteria, increasing compensation, and making compensation available in combination with home support.

1.5.2.2 Surviving the "caregiving trap": Caregivers' personal needs

"As caregivers we feel we have no life of our own, our time is needed constantly."

Despite the fact that many of these caregivers believe that caring for someone has intrinsic rewards and positive value, despite the objective differences in their circumstances and levels of burden, the subjective experience of these women is that, ***"As a caregiver, you are living constantly with stress and ongoing stress can make you ill; and no pill can fix that. If caregiving becomes all consuming one can lose their identity. Emotions can build causing anger and frustration; family breakdown can even occur."***

The second strong theme emerging from caregivers' insights is surviving the trap that caregivers fall into of becoming dangerously overburdened. They are overwhelmed by isolation, loneliness, financial insecurity, fear, exhaustion, confusion, desperation, helplessness, guilt, loss of identity and the frustration of dealing with a maze of bureaucracy. The "trap" is the failure to cope with the physical and emotional burden, leading to burn-out: stress-related symptoms and illness that render the caregiver unable to function effectively as a caregiver. These caregivers worry about the consequences to themselves and those they care for if they become ill: ***"If we do not take care of ourselves physically, mentally, and spiritually, we then become invalids ourselves."***

Coping with stress or surviving the trap involves not only having practical needs met to relieve the caregiving burden; survival for these caregivers also involves self-care. They told us that, ***"Because [we] are 'caring' [we] tend to be givers rather than takers...As caregivers, we need to acknowledge our own inner wisdom, to trust that our needs count and we too deserve to have them met."*** They recognize the importance of self care and feel they must learn to distinguish between what they are *able* to do and what they are *expected* to do, to take as well as to give. Caregivers feel they can cope better with the stress of caregiving and the feelings it engenders, if only they can have more time to rest and nurture themselves, physically, mentally, and spiritually: ***"A quarterly relief of one week time blocks would replenish and refresh the caregiver."***

1.5.2.3 Health care system issues for caregivers

" Lack of implementation of adequate homecare services by the government, as promised during the health care cut-backs, has caused rural areas to suffer greatly,"

One of the major priorities for this group of caregivers is making the health care system more responsive to their needs. There is a high level of frustration with the health care system. They feel that the current system, from pre-discharge assessments, to the full range of Home Care N.S. services, particularly Home Care assessments, respite, and home support workers, is not working for them. They feel that care given often is not appropriate to their needs or the needs of those they care for. As primary care providers, they want more say about who provides subsidized care and how it is provided.

There is a sense that the government has not kept the promises it made, to provide comprehensive community care, when closing and down sizing hospitals: ***"There has been a deterioration of care and services over the past several years. Services [have been] eliminated or changed with no replacement of these services even though they were promised by politicians during elections."*** These caregivers feel that the rural communities and small towns where they live have been especially hard hit by health reform, and that significant health resource inequities exist between urban and rural areas of Nova Scotia. They find it difficult to navigate the health care bureaucracy, often ending up in blind alleys. For instance, when local or regional health officials contradict statements made by provincial bureaucrats about Home Care benefits or eligibility for assistance, caregivers frequently give up trying to get help out of frustration and helplessness.

Above all, these caregivers are dissatisfied with current respite programs: ***"The system says respite is in place and working -- it is not!"*** There was virtually unanimous agreement that current respite allocations -- four to eight hours per week -- are inadequate, and difficult to access. Living in small towns and rural communities compounds the need for more than the current respite allocation Travel time for virtually any kind of errand or task outside the home, means that it takes rural residents longer to get things done. For caregivers to keep doctors and dentists appointments, they often must travel to Halifax. They told us that a single appointment can exceed an entire week's respite allocation, leaving no time for a rest from responsibilities. Caregivers need more respite time to ensure opportunities for rest, and varied respite programs, including long-term respite, and working respite and access to respite on short notice and in emergencies.

"Often we don't have any input into who is provided through Home Care N.S. We need more choice in who we think is appropriate for our loved ones, more involvement in the decision making." Caregivers said they are frustrated by a system that maintains they are "partners" in community-based care, but does not acknowledge the primacy of their role with respect to those receiving care. They feel that, ***"Sometimes we know that our decisions are right, regardless of what the system tells us."*** Health professionals discount or undervalue their deep knowledge of those they care for when decisions about homecare are made, resulting in inappropriate, inconsistent or disruptive care (e.g., the inability to provide the same home support worker each time for Alzheimer's patients who are notoriously fearful of strangers; the paucity of male home support workers to do personal care for elderly men). They want, ***"..more choice in who we think is appropriate for our loved ones, more involvement in the decision making for the [home support provider]."***

Caregivers told us that homecare assessments often do not take account of capabilities and limitations of the caregiver and the family situation: what they are *expected* to do frequently is not in line with what they are reasonably *able* to do. In addition to support and training to improve their capabilities, they ask that ***"...the health care system ...assess accurately and sensitively the needs of people...[including] knowledge and training of the caregiver in that situation. Home Care should give help that is actually needed, not what they think is needed."***

1.5.2.4 Valuing caregivers' work

"Caregivers are the unsung heroes of the homecare system and our government doesn't give a RIP!!!"

This group of caregivers believes that, ***"Society puts little value on caregiving. Caregivers need to feel a sense of pride and recognition for their jobs in the community".*** The sense that caregiving is work that deserves to be validated and valued by society is strongly felt and widely shared among these caregivers. They wish to be ***"...recognized by family members that [we] have a full time 24-hr./day, 7-days-a-week, highly intensive job. Acknowledge, recognize and appreciate us please!"***

Half of these caregivers had left or changed paid employment to become caregivers, and fewer than a quarter of them have paid employment currently. As (mostly) full-time caregivers, they are precluded from earning a living. They believe their caring work is important and should be compensated, and they ask, ***"Why are caregivers not paid for the service they provide? In Australia...they are paid for their service, [and they] pay into a pension plan ..."*** They feel that by not paying them, the government is signaling that it doesn't value their contribution to "community-based" care. This suggests that if the goals of community based care are to be achieved and sustained, the issue of compensating family caregivers must be addressed as a matter of policy.

Finally, some of these caregivers do not want to be referred to as "informal caregivers" because ***"...there is nothing informal about this job...we are primary caregivers... and because words speak volumes, we need to get the terminology right" .*** They need to be recognized as *primary* care providers: those who are directly and continuously responsible for the survival and well being of those they care for. They need to be given the resources -- information, training, respite, recompense -- to be effective caregivers.

Viewing homecare needs through a client lens that includes caregivers offers the opportunity to re-focus homecare priorities. Acknowledging caregivers' primacy leads to recognition that in most instances, the "client" of homecare programming is not just the "patient". In general, homecare resources spent on patient care benefit only the patients; they do not change the burden for caregivers and other family members. In contrast, resources spent supporting caregivers are likely to have a multiplier effect: benefits should accrue not only to caregivers themselves, but also to those they care for (improved care) and other family members .

1.5.2.5 Secondary themes

The remaining themes also reflected significant issues for caregivers. These associations with caregiving experiences were not as widely shared among participants, however:

- **community responses to caregivers and care recipients**

- **positive aspects of caregiving**
- **impacts of caregiving on other family members**
- **transportation in rural Nova Scotia**
- **making caregivers' voices heard**

We consider the latter set to be second order priorities as they do not seem to represent the same "pressure" for virtually all caregivers in this group as do the first set of themes. For some caregivers, for instance, "impacts on other family members" are not part of their caregiving experience, as they are living alone with those they care for. Likewise, concern about "community response to caregivers' loved ones" is of great import to caregivers of disabled/chronically ill children, who hope to see those children become integrated into their local communities, but of little significance to those caring for frail elderly family members who are confined to home.

Positive aspects of caregiving were associated with feelings of fulfillment for providing loving care and knowing that loved ones were happier at home, but it was clear that for many individuals in this group, fulfillment from the caregiving role was overridden by, or at least secondary to, feelings of burden and stress. Being constrained by lack of public transportation and the time-distance burden of virtually all rural travel are issues that seem to be common in the four regions of Nova Scotia where these caregivers live. Relatively speaking, however, concerns about transportation in rural Nova Scotia are not a pressing priority for this group.

Similarly, although there was widespread recognition among these caregivers about the importance of making caregivers' voices heard in order to get caregiver issues on the political agenda, advocacy was a high priority for only a few. This is not surprising, perhaps, given the time burden for most caregivers. There is clear need for advocacy on behalf of caregivers. Caregivers have a wealth of practical knowledge and want their voices to be heard. Caregiver advocacy efforts require support from government, which can benefit from engaging caregivers as partners in the policy process.

2. Research Implementation

2.1 Role of Advisory Committee

One of the innovative aspects of this research was the considerable involvement and influence of the Advisory Committee on the study. We explicitly intended to be guided by the deep knowledge and experience of Advisory Committee members with caregivers and caregiver issues. We had specified the research objectives and framework in advance, but allowed the Advisory Committee to shape the research content in significant ways.

For instance, after considerable discussion about how to define "caregiving" for purposes of selecting participants, the Advisory Committee decided that the Nova Scotia Health Survey 1995 definition would be used, with discretion, by site facilitators (see Appendix

H for definition). This proved to be a practical and effective approach. It gave site facilitators leeway in finding participants, and resulted in a sample that matched the research criteria in all respects, except for inclusion of immigrant women.

The Advisory Committee also led us to keep the story theme broad: "your personal experience as a caregiver". As a generative theme -- i.e., one that would stimulate discussion -- this proved to be highly effective. In terms of form and content, there was considerable variation among the 20 written stories which we received, according to individual's circumstances, writing abilities and story telling skills. Overall, the quality was higher than we had expected, given uncertainties about the levels of literacy we would encounter among caregivers in our study.

The Advisory Committee also contributed to the research process in significant ways by choosing the research sites, suggesting names of potential site facilitators in those locations, reviewing and commenting on questionnaires and workshop materials, suggesting evaluation approaches and dissemination strategies. They contributed in material ways by providing meeting space, secretarial services, and expense sharing on workshop trips.

At four Advisory Committee meetings, held in February, March and April, the research objectives were reviewed, a schedule of project activities was developed, research sites were selected and suggestions for site facilitators made, story dialogue methodology and questionnaires were reviewed, and evaluation and dissemination strategies were developed.

2.2 Were Objectives Met?

The primary objective of this research was to generate practical knowledge about gaps in existing caregiver supports, based on caregivers' perceptions. A secondary objective was to demonstrate the value of sharing stories as a community-based research approach which would engage caregivers and encourage collective processes, mutual support and advocacy. Both objectives were met, as detailed below.

2.2.1 Generating practical knowledge

The major themes identified above -- valuing caregivers' work, surviving the caregiving trap, caregivers' practical needs, and health care system issues for caregivers -- represent the views of caregivers. The knowledge derived from these caregivers' analyses of their stories emphasizes dissatisfaction and frustration with current supports available to them, from families, communities and service providers.

To the extent that we received specific, directed suggestions for assistance, services and programs they would like to see, we fulfilled our primary objective. Nevertheless, we began this research expecting to learn about the supports caregivers are currently using, and how these fall short of what they need. However, these caregivers told us little about which services, assistance, and providers are currently in place and working well for them. Instead, they focused on their overwhelming needs for support from the formal care system. Thus, it is difficult to distinguish gaps in support from what appears to be a virtual support vacuum.

This emphasis on what is *not* working and the pressing sense of need communicated by these caregivers may be in part a reflection of the generative theme they were given: if instead of asking them to tell us about what supports they need, we had asked them to tell us about what supports were working for them, another set of themes may have emerged or the balance might have been different. Possibly they would have emphasized how to improve upon existing supports and services.

It stands to reason that many of these caregivers have supports in their communities (one example which comes to mind is a local health clinic in Cape Breton which was identified as an important information resource for caregivers in that community). Nevertheless, without detailed information about which supports they are using, it is difficult to offer insights from these caregivers, on *specific* possibilities for "caring partnerships" in their communities (cf., Keating et al, 1997). We cannot, for instance, provide independent support for the conclusion of the Centre on Aging study that the VON should have a coordinating role in services to caregivers, because we have no information from this group about how the VON currently serves them.

The pressing needs these caregivers identified *imply* much about existing supports, or absence of supports. More importantly, they represent practical knowledge in terms of specific examples of assistance caregivers require in their daily lives, especially for information, respite, training and compensation. If this research illuminates and raises the profile of these needs, then the research fulfills the primary research objective. Further work is required, however, to determine which organizations, institutions and service providers are currently meeting caregivers' needs in local communities around Nova Scotia.

2.2.2 Storytelling as community-based research approach

This research was not designed as an intervention, or as "action research" *per se*. We did not set out to "change" this group of caregivers. Nor was this participatory research in the classic sense: the participants had no role in setting the research agenda. Nevertheless, we hoped that the process of sharing their stories would, in Hooyman and Gonyea's words, validate their experiences as caregivers, and this seemed to happen. Some mentioned they had never revealed their thoughts and feelings about caregiving. Participating in the workshops allowed them to speak the "unspeakable" -- occasional wishes for the suffering of their loved ones to end, and with it, their burden; their need to put themselves first once in a while; their resentment toward other family members, etc.

By having an opportunity to value one another as caregivers, by collectively giving voice to their feelings and beliefs about the caregiving experience, caregivers may begin to feel empowered. If participation in the story dialogue workshops was an empowering experience, then perhaps some participants might be mobilized as a result of their participation. Indeed, several exchanged phone numbers, to keep in touch with other workshop participants. Some said they had been re-energized and would revive a support group which had lapsed. Others with whom we have been in touch subsequently, are anxious to become active participants in a new family caregivers association.

Among those who may have felt most empowered were the site facilitators. These women told us they found the experience of recruiting study participants, telling and analysing their own stories in the training workshop, and assisting with the research workshops gave them renewed purpose and energy. One of the site facilitators, in collaboration with a workshop participant, and one of the researchers (Gail Bruhm) is currently establishing a provincial association for family caregivers. Another site facilitator is helping to revive a caregiver support group in her region. A third individual, who coordinates the local women's centre in her region, has decided to seek funding for a caregiver support group to be run from the centre. It is unlikely these activities would have happened, or happened when they did, without the workshops.

Thus, it seems clear that we fulfilled our secondary research objective.

2.3 Evaluation

The primary objective of this research was to generate practical knowledge for policy makers based on caregivers' perceptions of their support needs. A secondary objective is to demonstrate the value of the story dialogue method as a community based research tool.

The evaluation plan, developed in consultation with the Advisory Committee, included three aspects:

- participants' ratings of the workshops as an opportunity for social support, and a method for making their voices heard;
- ongoing monitoring of the research process and documentation of progress and challenges, in minutes of Advisory Committee meetings (Appendix I); and
- an assessment of the research findings in terms of their value to policy makers.

Workshop participants were asked to evaluate the workshops in a brief questionnaire (see Appendix J). Nine items were rated on a five-point scale, including feelings about other *participants*, the workshop *method* as a vehicle for self expression and learning, and the *overall workshop* as a means of making a difference in the lives of caregivers. Participants were also invited to explain any of their responses or make other comments.

Forty-one caregivers completed the workshop evaluation. Ratings were consistently high for all items (see Table 3). A large majority of participants felt that they were with people they could trust and had a lot in common with. More than half indicated that they had met people they wanted to stay in touch with, though this item was rated somewhat less positively than the other eight items. A majority of those who completed the questionnaire felt they had been able to say what was on their mind, and that the process was a good way to learn from their own and others' experiences. As well, most indicated that the workshop made them feel better about their situation. They felt that their voices were heard, and that their participation would contribute to changes that could help all caregivers.

Advisory Committee minutes, for meetings from February to September are presented in Appendix I. Examination of the minutes confirms that the research process proceeded as planned, on schedule, in consultation with the Advisory Committee. No major obstacles or delays were encountered.

Table 3: Evaluation Questionnaire Responses (percent) (N= 42)

	STRONGLY DISAGREE			**STRONGLY AGREE**	
Response Scale	***1***	***2***	***3***	***4***	***5***
Participants					
Felt I was among people I could trust	-	-	5	15	80
Met people whom I have a lot in common with	-	2	7	10	80
Met people whom I want to stay in touch with	-	-	12	24	59
Method					
Was able to say what was on my mind	-	-	2	18	80
Good way to learn from *your own* experiences	-	-	5	20	75
Good way to learn from *others'* experiences	-	-	2	18	80
Overall Workshop					
The workshop made me feel better about my situation as a caregiver	-	-	10	15	75
Feel my voice was heard	-	-	10	15	75
Feel that my participation may contribute to changes that could help all caregivers	-	-	10	17	73

The draft Executive Summary was circulated to all workshop participants and site facilitators. They were asked to tell us, by mail or phone, if they felt the summary did not reflect their views of the important issues for caregivers, and if not to let us know what was missing. Of the six five caregiver and one facilitator who responded, all responded positively to the results as summarized, and expressed their full agreement.

The Advisory Committee recognized that the evaluation component of the research would be limited, of necessity, by the lack of budget for this aspect. After discussion of what was feasible, it was agreed that in addition to participant evaluation of the workshops and monitoring the research process at Advisory Committee meetings, the usefulness of the research results to policy makers would be addressed by polling an audience of policy makers . Thus, a broad spectrum of policy makers involved in homecare and community care were invited, along with interested others, to attended a presentation of the research findings hosted by the Maritime Centre of Excellence for Women's Health. All those who attended were given a brief questionnaire asking them to evaluate the research for its usefulness for policy (see Appendix J).

Of the 26 people who attended, 14 completed the evaluation. Four respondents indicated they were involved in developing or implementing homecare policy. Half indicated they would be likely, "to a significant extent" to use the research findings in their work. Half responded the research would be "somewhat" useful in their work. All respondents were asked about the usefulness of the research to homecare policy and programming "in general". Eight out of ten who answered the question said the research is useful "to a significant extent", and two said "somewhat". Suggestions for making the research more useful for homecare policy and programming included, developing a user-friendly communication tool, sending the Executive Summary to health ministers and senior bureaucrats, publishing excerpts of the research in magazines and newsletters, and making presentations to health department and regional health board staff(s).

Finally, the Advisory Committee expressed a desire to provide their evaluation of the research process through an organized reflection process initiated by the Maritime Centre of Excellence for Women's Health.

3. Dissemination/Knowledge Sharing

The Executive Summary will be widely distributed, to bureaucrats, politicians, non-government organizations, participants, and interested others. Those who wish to have the longer report, with details of the research process, research literature, etc. may request it from the Maritime Centre of Excellence for Women's Health.

The cornerstone of the strategy for disseminating research results to policy makers is the Advisory Committee consisting of stakeholders from provincial and federal governments and non-government organizations. Advisory Committee members have agreed to bringing the project final report forward to their respective institutions /organizations. ensuring that the results are directed to relevant personnel, and following up as necessary. The possibility of meeting with provincial health officials to discuss the project results is being pursued.

We presented a proposal for a poster based on the results of this research accepted at the Canadian Association on Gerontology annual meetings, which occurred in Halifax in October 1998, and at a Lunch and Learn presentation hosted by the Maritime Centre of Excellence for Women's Health. The Centre also issued a press release to publicize the report, and has plans to circulate the report nationally, through the Centres of Excellence for Women's Heath network.

Apart from these activities, more innovative ways of sharing the research results will require additional investment of resources by the Maritime Centre of Excellence for Women's Health. If additional funds can be found, we suggest preparing a presentation package for Advisory Committee members and others to use with a variety of audiences. In addition, the Committee suggested that an organized policy discussion including caregivers be held as a follow-up to the National Homecare conference, possibly co-hosted by the regional office of Heath Canada and the Maritime Centre of Excellence for Women's Health. This possibility is being pursued. Another suggestion is to present the results of this research to a meeting of the Maritime Council of Premiers.

Depending upon demand and availability of additional funds, we also suggest presentations be organized in the communities where the original workshops were conducted so that the knowledge gathered from caregivers will be shared with them.

Finally we hope that the newly established Family Caregivers Association of Nova Scotia can be used as a vehicle for making the results known to caregivers around the province. Again, availability of funds (for the organization) will be the key to success.

4 Implications for MCEWH Mandates and Research Programs

4.1 Generating New Knowledge

In this investigation, women caregivers living in rural areas of Nova Scotia told us that the burden associated with caregiving responsibilities is considerable. They need support, in terms of services tailored to actual needs, and information on how to provide care effectively. They need relief from the stress of caregiving and time for self-care so that they can remain healthy and continue giving care.

This knowledge is new in two senses. First, it is unique because it comes from caregivers' own analysis of their lived experience, as told in their stories. As such, it is genuine, and has emotional and moral weight that makes it difficult to ignore. Second, this knowledge is new in the sense that it shifts the emphasis on family caregiving from "informal" to "primary" care, re-positioning caregivers at the centre rather than the periphery of homecare policy.

4.2 Producing Information Reflecting Gender-Based Realities

The composition of this research sample makes a powerful statement about the gendered nature of caregiving: despite a conscious choice not to exclude men from this study, we ended up with a sample that did not include any men. Despite presence of husbands, sons, fathers and brothers with ties to those being cared for, the 46 women who participated in the study are the primary (and many sole) caregivers of parents, spouses, in-laws, siblings and disabled/chronically ill children.

Another key area of information for gender-based analysis is valuing women's work. These women do not necessarily consider the fact that they are contributing to the economy and subsidizing health care reform in terms of gender equity. Nevertheless, having their work valued in economic terms is important to them. We calculated that if a full-time caregiver was paid at the rate of $10.90/hour (GPI Atlantic, 1998) for providing 24 hours of care, 365 days per year, she would earn roughly $95,500 annually. Subtracting $3328 which the provincial government will spend on respite (8 hours/week), the savings from this hypothetical caregiver to the health care system annually through replacement of institutional services with her labour is approximately $92,000.

4.3 Disseminating Information and Establishing Networks

An important purpose of this research was to give caregivers the opportunity to make their voices heard. To some extent, this purpose was realized even before this report was written, in that caregivers were given the opportunity to tell their stories (many for the first time) and discuss them with one another. Some of those caregivers are still talking -- to one another, to politicians, and to others interested in forming a formal network of caregivers in Nova Scotia. As well, the four site facilitators have expanded their own local caregiver networks as a result of their work on this project, and may be instrumental in developing and maintaining a provincial network.

In addition, the group of committed stakeholders on the Advisory Committee who volunteered many hours of their time to this project were partners in this research. They have a vested interest in spreading the word among their own networks in government, universities and the volunteer and non-government sectors.

4.4 Providing Policy Advice

This research was designed specifically to gather knowledge for policy. Most of the themes emerging from caregivers' analysis of their stories are related to needs for programs and information provided by governments. The recommendations arising from caregivers' insights -- for governments to view caregivers as primary care providers and to provide services, especially, respite, information, training and compensation -- should be of greatest interest to provincial health officials and federal health officials responsible for the national homecare initiative. It is clear from this research that participation of caregivers in developing homecare policies, though support of and partnering with caregiver advocacy groups will be a key to ensuring that programs and services meet the real needs of caregivers.

4.5 Maritime Centre of Excellence for Women's Health Research Programs

The focus of this study was not determinants of health *per se*. Nevertheless, these caregivers identified certain broad socio-economic factors which influence health and well being -- rural residence, social isolation, limited employment and income opportunities -- as factors contributing to their burden. In a population health framework, gender is also recognized as an important health determinant, as a social factor associated with the gendered division of labour which subordinates and disadvantages women. This group of caregivers exemplifies the gender bias which regards women as "natural" caregivers and ghettoizes caregiving as unpaid women's work. The caregivers in this study do not consider themselves to be victims. Nevertheless, their health and well-being is clearly subject to the influence of social, economic and cultural forces beyond their control and not of their choosing.

The study addressed Research Program 1 -- *women's perceptions of their health and health determinants* -- by examining women's experiences as caregivers. Having women share and analyse their caregiving stories illuminates the personal meaning of caregiving and women's concerns about the impact of caregiving on their health by suggesting factors that caregivers perceive as influencing their health, especially, social isolation, rural-urban resource inequities, and income and employment constraints.

This research also is relevant to Research Program 2 -- *determinants of health of marginalized women living in disadvantaged circumstances.* Gender inequity underlies the caregiving role. By definition, women who are caregivers are marginalized. Because they are usually socially isolated, often unemployed or under employed, and labouring under time demands and stress which make it difficult for them to engage in health promoting behaviors, they feel trapped by this burden and fear it will lead to physical and/or emotional breakdown.

4.6 Implications for Policy Making

This research sought to gather practical knowledge about rural family caregivers' needs *from the perspective of caregivers.* The contribution of this research to the development of programs aimed at improving the health of caregivers is that it "breaks the silence" of caregivers, by enabling them to voice what they need and to assert their primacy as care providers. Acknowledging their primacy allows us to position caregivers as "clients" of homecare programming. The knowledge we gathered is based on the meaning of individual and collective caregiver experiences. Through this research, caregivers themselves are speaking to policy makers, offering a new client lens for homecare policy.

The caregivers in this study made many specific suggestions for programs and services that would provide practical support. These are presented in Appendix G. Below are the broader messages from caregivers to policy makers that emerged from this study. Caregivers must be addressed directly and included in developing policy responses. We hope that readers involved in policy development will make systematic efforts to seek out caregivers and engage them in discussions about these messages.

4.6.1 Recognize caregivers' contributions

Caregivers tell us that the health care system (planners, decision makers and providers) does not acknowledge, appreciate or support their contribution as the primary care providers for those who without their care would require institutionalization. In the view of these caregivers, failure to recognize the primacy of their role results in frustration on their part and programming and services that are inappropriate to the needs of the clients they are meant to serve. Progress in policy development can be made by incorporating caregivers as key to the ultimate success of homecare programming

4.6.2 Engage caregivers in the policy process

Although the Nova Scotia' s Blueprint for Health System Reform (1995) recommended that informal caregivers be included in policy development and planning, caregivers feel they have not been included. They believe their knowledge, experience, personal stake in the outcomes and their contribution to the health care system as primary caregivers give them a central role to play in homecare policy development. They have many practical suggestions for supports and services, and they are prepared to make their voices heard. Improvements will result in policy and programs if caregivers are partners rather than adversaries in the decision-making process.

4.6.3 Provide support services and information

The caregivers in this study feel the government broke the promises it made when closing and down sizing hospitals, to provide comprehensive community care. They feel burdened by their responsibilities. Absence of promised services, information and training appropriate to their needs -- especially respite options -- contributes in great measure to their burden. The burden of caregiving with inadequate supports traps caregivers in a downward spiral of stress and ill-health that erodes their effectiveness as caregivers. They need services, information and training to be as up-to-date and available to them in rural Nova Scotia as the best services, information and training available in Canada. They know what they need and have many practical suggestions to offer.

4.6.4 Value caregivers' work

Caregivers' unpaid labour is a substantial contribution to the economy; it subsidizes health reform to a significant extent by substituting costly institutional care with virtually free home care by family caregivers. This substitution is possible because of prevailing values which regard caregiving as "women's work". These caregivers need to be compensated for their work. Sustainability of a community based heath system that relies on family care depends upon providing compensation and pension benefits.

4.7 Conclusion

The information produced by the Caregivers Research Project goes well beyond documenting needs. The "story dialogue" approach allowed for the capture of insights and knowledge which are grounded in the personal experience of caregivers. The insights contained in the report will be of considerable value to everyone directly involved in homecare, and to anyone interested in enhancing the well-being of families in rural communities.

Notes

1. *The definition of "caregiving" used in this research is borrowed from the Nova Scotia Health Survey 1995 (see Appendix H). "Informal" is used here to denote the unpaid nature of family caregivers' work. Its use is not intended to diminish the sense of the primacy of the relationship between family caregivers and those they care for.*

2. *Story-dialogue training and the first workshop were led by Susan Lilley. The following three workshops were led by Joan Campbell.*

3. *Caregiver comments are presented throughout the text in bold italics. Editorial changes to caregivers own words (apart from spelling corrections) are enclosed in brackets [ ].*

4. *The suggestion that those under 65 are "employable" refers to current employee age norms. We do not mean to suggest that persons 65 and over cannot or should not be employed.*

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Appendix A: Advisory Committee Membership

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Appendix C: Methodology

Participant Recruitment

Site facilitators contacted potential participants by telephone. After identifying themselves, explaining their connection with the research project and providing the name and telephone number of the research coordinator, they gave a brief explanation of the study and asked if respondents would like to know more and perhaps consider participating.

A letter was sent to those who were interested, explaining in detail the goals and nature of the study, the format of the workshops, expectations of those who agree to participate, the intended use of information obtained in the workshops, the emphasis on keeping all participants' information confidential and the names and telephone numbers of the site facilitator and the research coordinator respectively (See Appendix K).

Letters were followed up by a second telephone call from site facilitators, who identified themselves and asked respondents if they received the letter. Assuming a respondent had received the letter, the site facilitator then said, "Before we go any further, let me assure you that everything in our conversation today will be kept in confidence, whether or not you agree to participate in the study. Are you interested in participating in this study? Do you have questions?" Those who declined to participate at this stage were asked, "For completeness of our information, are you willing to share with me your reason for not participating?" No further prompts were made. If a respondent preferred not to give a reason she was thanked for her time and the conversation was terminated unless the respondent had questions.

We instructed facilitators to answer all respondents' questions about the study to the best of their ability. Respondents were invited to call the research coordinator collect if, after speaking to the site facilitator, they still had questions or concerns. No phone calls were made to the research coordinator.

Workshop Process

Each participant was given 12 to 15 minutes to share her story with two or three other women (for examples of stories, see Appendix L). Participants had been asked in advance to, "tell a story about your personal experience as a caregiver and the supports you need to be effective" preferably in writing. We felt that the theme of "personal experience as a caregiver" was sufficiently generative (i.e., likely to stimulate animated discussion) that it did not require further focus, as important issues would arise in discussions.

Reflection upon each story involved approximately 20 to 30 minutes (per story) of small group discussion, guided by four questions: *what* happened (description)?, *why* did it happen (explanation)?, *so what* does this tell us about caregivers (synthesis)? and, *now what* should be done about it (action)?

We gave participants instructions about recognizing "insights" during their discussions (see Appendix K). Each group designated one individual to record insights during the discussions -- a single insight on one sheet of paper. We provided paper and coloured markers for this purpose, and indicated that the collected insights from the morning discussions would form the basis for the afternoon session.

In a second level of reflection, participants gathered insights from all story groups into categories in a plenary session. Collectively, they decided which insights belonged in which thematic groups. Once all the insight sheets had been assigned to categories, pairs of participants each selected a category to develop as a narrative statement. They spent approximately one to one half hours constructing statements which captured the insights and presented the essence of the category in a logical and cohesive fashion. They wrote these in narrative form, in their own words. The researchers were available during this time to answer questions and give encouragement to those who needed it.

These narrative statements represent caregivers generalizations from analysis of their collected stories. They formed the core data for analysis. A total of 37 narrative statements were developed in the four workshops.

We also obtained descriptive data on caregivers from questionnaires that were completed at the workshops (Appendix D). The questionnaire was pilot tested in advance on a small sample of caregivers known to the authors. Informed consent was obtained at each workshop (Appendix K). Participants also completed a brief evaluation of the workshop at the end of the day (Appendix J).

Finally, we sent participants whose stories were selected to appear in the final report a copy of the prepared text for review. We encouraged them to make any changes they felt were necessary, and indicated that we would remove individual's and place names that might identify them or their families.

Appendix E: Results

Of the 46 caregivers who participated, 13% (n=6) were Black, 4.3% (n=2) were Aboriginal, and 6.6% (n=3) were Acadian (Table 1). All participants were women. Although men were not excluded from selection, the overwhelming majority of those contacted initially were women. One man who agreed to participate did not show up. Half of the participants were between the ages of 31 and 50 (50%, n=23). Roughly one third (34.8%, n=16) were between 51 and 65. Fewer than 10% (n=4) were over 65, and only one (2.2%) was under 31 years of age.

We did not ask participants directly about income, as the Advisory Committee deemed this as too personal to ask participants about in the workshop. Instead we adopted a surrogate measure of lack of income to buy food, using a question from the Adult Hunger Scale (Olsen, 1992): "Does your household ever run out of money to buy food?", and if so, how often. Fifteen per cent (15.2%, n=7) of these caregivers told us their households run out of money to buy food, occasionally (4.3%, n=2), quarterly (4.3%, n=2), or bi-weekly (6.5%, n=3), suggesting that some caregivers experience significant financial strain.

There is considerable variation in the caregiving situations of this group of women. We found that 87.2 % (n=41) were providing personal care on a regular basis to one individual. Of these, 31.7% (n=13) were caring for a parent, 19.5% (n=8) were caring for a spouse, 17% (n=7) another relative (in-laws, aunts), 14.6% (n=6) a disabled or chronically ill child over 16, 7.3% (n=3) a disabled or chronically ill child under 16, 4.9% (n=2) a friend who is not a neighbour, and 2.4% (n=1) a neighbour (Table 2).

Consistent with the recent finding of Beanlands and Macpherson (1997) that 23.2% of Nova Scotia caregivers are caring for more than one person, 12.8% (n=6) of caregivers in this study indicated they are providing care on a regular basis to *more than one person.* Caregiving combinations include spouse and parent (n=1), spouse, parent and other relative (n=1), parent and friend (n=1), parent and disabled/ chronically ill child over 16 (n=2) and parent and other relative (n=1). (Table 2)

How much time are caregivers spending providing care? To answer this question, we asked participants to indicate which of six intervals, ranging from "24 hr/day, every day of the year, with no relief" to "a few hours each month", reflected their situations. The majority of these caregivers (78.3%, n=36)) are on duty 24/hr. day: 15.2% (n=7) told us they provide care 24 hr./day "with no relief", while 63% (n=29) get "occasional relief" from being on duty 24 hr/day (Table 2). A few (6.5%, n=3) are called upon to provide 24-hr. care a few days at a time (e.g., weekends), a few hours each day (8.7%, n=4), or a few hours each month (4.3%, n=2).

Caregiving responsibilities are not limited to caring for seniors. The ages of those being cared for by this group covers the life span: 13% (n=6) are caring for someone 18 or under, 19.6% (n=9) for an individual aged 19 to 65, 32.6% (n=15) for someone aged 66-80, and 34.8% (n=16) are taking care of someone who is between 81 and 100 years old.

In response to a question about whether the person being cared for lives in the caregiver's home, 69.6% (n=32) responded affirmatively. For 18.7% (n=6) of these caregivers this meant moving into the home of the person they were caring for. For those *not* living with the person being cared for, the mean travel time to reach that person is 16.9 minutes. (Table 2)

In most instances, caregivers are the sole care providers. More than two thirds of this group of caregivers (69.6%, n= 32) told us that they are the "only one" providing care on a regular basis. For those who have assistance, spouses and siblings were most frequently identified as the persons who help out.

Caring for a family member or friend is a long term proposition. As a group these caregivers have been providing care for an average of 7.4 years. While 30.4% (n=14) of them have been "on the job" for under two years, the same proportion has been providing care for seven to 15 years; 26.1% (n=12) for between three and six years, and 10.9% (n=5) for 16 to 40 years. (Table 2)

One of the biggest sacrifices many caregivers make is employment. In this group, 23.9% (n=11) have paid employment. Those who are employed work an average of 22.2 hours per week. Of those who do not have paid employment, 50% (n=17) report leaving or changing a paying job because of caregiving responsibilities (Table 1).

Appendix F: Themes and Insights

(Primary Themes)

1. Practical needs of caregivers

Services and supports

specific resources
community clinics as focal points for services and information
pagers/beepers for caregivers (paid and unpaid)
internet
woodland retreat centre for caregivers
workshops to raise family members' awareness of caregiver needs
public orientations to nursing homes for adults and children
support from professionals, classes on "how to caregive"
exercise and recreational facilities
counseling services
clinics staffed with qualified people
1-800 number for counseling, medical, legal and "red-tape" assistance
government sponsored clinics with information., services and staff for caregivers
centres in local communities for elder care (several times/wk.)
isolation unnecessary
caregivers support groups
association for caregivers
caregiver network, incl. list of support groups
service club volunteer programs for "care receivers"
friendly neighbors to call, run errands
friends and family to visit
family to help
ask, "How are you" instead of "How is your mother"
help from time to time
network of volunteers for domestic chores (e.g., local service clubs)

Information and training

community education: videos, telephone directory services, 1-800 number
resources, information in public buildings (e.g., post office, credit union)
directory of experts, advice and sources of financial assistance (for equipment etc.)
community liaison person for caregiver resources
information available in public places: clinics, libraries, internet, etc.
training of help-line workers to respond to caregivers
helping organizations to update information about available resources
learning about illnesses, needs of care recipients
preparing for the "caregiving crisis"
preparation for the caregiving role

directory of information
internet resources
programs needed for caregivers in the community

Financial assistance

not enough money
financial assistance not available to family caregivers
cost of long term care approximately, $40,000
pay caregivers
income tax credits for caregivers
assistance for home renovations (e.g. ramps. bathrooms, etc.)
eligibility requirements (for assistance) based not just on income but also on specific requirements (medication, special foods, transportation, medical supplies, equipment, etc.)
caregivers often financially dependent on those they care for
caregivers often financially responsible for other family members
caregivers need to know their rights
community based co-operatives where members contribute for necessary services (esp. for emergencies)
support from provincial and federal governments

2 Caregivers' personal needs: surviving the "caregiving trap"

"caregiver trap:" stress, loss of independence, isolation, loneliness, financial insecurity,
maze of red tape, confusion, fear, exhaustion, desperation, helplessness, overburdened, guilt, loss of identity
nurturing the caregiver
acknowledge our inner wisdom
look after ourselves: set boundaries; care for ourselves
know what we are <u>able</u> to do vs. what we are <u>expected</u> to do
awareness of the "trap" of caregiving: caregiver burnout
"Me Time" (1-2 days/wk; 2 wk. minimum; 1 weekend/ 3 wk.
overcome fear and guilt
time for (caregiver) personal care = additional respite time
givers and takers
sacrificing careers, hobbies
hesitating to ask for help
guilt about not meeting expectations
no time for spouses, children
no time for ourselves
living within the shadow of the care receiver
care for ourselves: physically, mentally spiritually

3 Health care system issues for caregivers

health care services have deteriorated; political promises for replacement services not kept rural areas suffering because of government failure to implement adequate Homecare services promised with health care restructuring
respite system is not working!
greater involvement needed in selection of Homecare workers
continuity and consistency of care: same provider each time
to help ensure good match of care receivers and Homecare workers: exchange information
male Homecare workers needed
increase Homecare workers pay to attract qualified staff, esp. men
review Homecare N.S.
Homecare assessments based on needs and circumstances of each individual situation
provide extended care
government must re-evaluate needs of communities with respect to caregiving
often it takes 2 Homecare workers replace one family caregiver: what does this suggest?
Homecare workers should be trained and expected to perform simple medical tasks (e.g., administering prepared medications)
sensitive and accurate pre-discharge assessments needed, incl. knowledge and training of caregiver
home support should be non-intrusive
long-term as well as short term care
assistance needed should be determined by caregiver and care recipient, not Homecare N.S.
allow more travel time for Homecare workers in rural areas
train Homecare workers to deal with common conditions, e.g., Alzheimer's
Homecare time allocations should sufficient to meet the needs in each situation
streamline the bureaucracy (too many channels)
care appropriate to needs
long-term respite care (e.g., one week per quarter)
travel time included in short-term respite allocations (rural need)
rural caregivers needs different from urban
consider individuals' needs, not system needs in developing care plan
range of options for caregivers working outside home, incl. "working respite"
caregivers fear losing control of the situation (esp. finances) if they ask for help
work with individuals in the bureaucracy who care

4. Need to value caregivers' work

appreciation
recognition
acknowledgment

training
pay for caregivers' work
not "informal": primary, natural caregivers
unsung heroes of Homecare system
sense of pride

(Secondary Themes)

5. Community responses to caregivers and care recipients

specialized support from qualified persons for special needs children
needs of these children change as they age
trained staff in schools
day camps for summer months
assistance tailored to individual
support from teen groups
community support
group homes
life seems meaningless without participation in community
involve care receivers in community functions
inaccessibility = lack of welcome
caregiving is a community issue
make businesses and public places accessible
public education re: needs (ramp is OK, but what about the bathroom?)
need elevators that work for seniors and disabled
lack of accessibility is viewed as lack of welcome
accessibility is a business issue: we'll take our business elsewhere
community support for disabled children functioning in and contributing to the community
caregiver support groups as community assets
re-educate (rural) doctors about caregiver support needs
(rural) doctors to work as a team with nurses, social workers, and Homecare N.S.
need community coordination of help for caregivers

6. Positive aspects of caregiving

feeling of fulfillment
knowledge that care receiver is happier at home
regular contact with care receiver, of care receiver with family members
loving care
familiar surroundings for care receiver
rewards of caregiving
helping to ease another's pain
contribution to the community

6. Positive aspects of caregiving (cont'd.)

creating memories and cherishing them
making the lives of our loved ones the best they can be
learning something new every day from those being cared for
acknowledge our inner wisdom

7. Impacts of caregiving on other family members

need support for family members feeling left out
feelings of other family members
communication with all family members
involving family in caregiving
plan future care needs with family members
strain on caregiver marriages
time away from caregiving for couples

8. Transportation in rural Nova Scotia

caregiver transportation issues: distance, travel time; lack of public transportation, cost of transportation, feeling trapped (rural)
community vehicle for geriatric and disabled for errands, appointments, leisure
time and distance coupled with insufficient respite time precludes visiting family, neighbours
many rural caregivers do not drive
travel allowance
more (respite) time for errands and actual travel

9. Making caregivers' voices heard

establish ombuds for caregivers
contact politicians about caregivers' concerns
lobby for adequate services
form a lobby group to raise political awareness of caregiver issues
lobby, lobby, lobby for adequate services

Appendix G: Practical Supports Suggested by Caregivers

Services in local communities

pagers/beepers for caregivers
exercise and recreational facilities
counseling services
government sponsored clinics with information., services and staff for caregivers
centres in local communities for elder (day) care
youth day camps for summer months
group homes for disabled youth
caregivers support groups
service club volunteer programs for caregivers and care receivers
network of volunteers for domestic chores

Information and Training

1-800 number for counseling, medical, legal and "red-tape" assistance
classes on "how to caregive"
workshops to raise family members' awareness of caregiver needs
public orientations to nursing homes for adults and children
community education: videos, telephone directory services
resources, information in public buildings (e.g., post office, credit union. library)
directory of experts, advice and sources of financial assistance (for equipment etc.)
community liaison person for caregiver resources
training of help-line workers to respond to caregivers
internet access and information

Financial

pay caregivers
income tax credits for caregivers
financial assistance for home renovations (e.g. ramps, bathrooms, etc.)
eligibility requirements (for assistance) based not just on income but also on specific requirements (medication, special foods, transportation, medical supplies, equipment)
community based co-operatives where members contribute for necessary services (especially for emergencies)
travel allowance

Home Care

long-term respite care (e.g., one week per quarter)
range of options for caregivers working outside home, including "working respite"
more respite time for errands and actual travel
male Home Care workers needed
Home Care assessments based on needs and circumstances of each individual situation
Home Care workers trained and expected to perform simple medical tasks (e.g., administering prepared medications)

Other

community vehicle for geriatric and disabled for errands, appointments, leisure
ombuds for caregivers
woodland retreat centre for caregivers
association for caregivers

Appendix H: Definition of Caregiving

> "Any type of help or care for a person with an illness, physical disability, mental handicap, mental or behavioural problem that has lasted or is expected to last 30 days or more, and does not include paid or volunteer work."

Definition borrowed from the *Nova Scotia Health Survey 1995.*

Appendix J:

1. Workshop Evaluation Questionnaire

Please let us know your feelings about this workshop by circling the number that best represents how strongly you agree or disagree with the following statements.

	STRONGLY DISAGREE				STRONGLY AGREE
The Participants					
1. I felt I was among people I could trust	1	2	3	4	5
2. I met people whom I have a lot in common with	1	2	3	4	5
3. I met people whom I want to stay in touch with	1	2	3	4	5
The Method					
4. I was able to say what was on my mind	1	2	3	4	5
5. It's a good way to learn from *your own* experiences	1	2	3	4	5
6. It's a good way to learn from *others'* experiences	1	2	3	4	5
The Overall Workshop					
7. The workshop made me feel better about my situation as a caregiver	1	2	3	4	5
8. I feel my voice was heard	1	2	3	4	5
9. I feel that my participation may contribute to changes that could help all caregivers	1	2	3	4	5

Please feel free to explain any of your responses or to make other comments.

____

____

____

____

Thank you!

2. Lunch and Learn Evaluation Questionnaire

The Caregivers Research Project was intended to provide practical knowledge from family caregivers in rural Nova Scotia that would be of use to those developing homecare policy and programming at all levels.

We are interested in discovering if the information presented today is useful, and would appreciate it if you would take a few moments to answer the questions below.

1. Are you involved in developing/implementing homecare policy/programming?

____yes ____no

If yes, in what capacity?____

Please circle the appropriate response:

2. If you answered "yes" to Question 1, to what extent are the results of this research, as presented today, likely to be of use to you in *your work*?

1 2 3 4 5 NA

not at all **somewhat** **to a significant extent**

3. To what extent are the results of this research, as presented today, likely to be of use for homecare policy/programming *in general*?

1 2 3 4 5 NA

not at all **somewhat** **to a significant extent**

If you have suggestions for making the results of this research more useful for homecare policy/programming, or additional comments, please let us know.

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Thank you for your assistance.

Appendix L: Caregivers' Stories

The stories of caregivers formed the basis for issues and insights captured as critical themes which were discussed in the body of the report. Their stories are compelling and rich in detail. They illustrate the ideas and concepts embodied in the themes, but more importantly, they give a human face to the issues of caregivers. The four stories which follow were selected to represent a range of caregiver situations and issues. They offer a window into the reality of caregivers' lives which mere generalizations cannot capture.

Story 1:

VICTORIES

> *(My son) was diagnosed with Duchenne (muscular distrophy) in March 1987, after much "running to and fro" to different doctors trying to put a medical name on what was wrong with (him.) After total shock, disbelief, denial and terror we struck out together on this new path in life to which we had been detoured.*
>
> *In 1991 we had reached a point in the disease where we realized that (he) would soon need a wheelchair and that we had better find a new home. At that time we were living in a second floor apartment (with no elevator or doors wide enough or bathroom big enough to accommodate a wheelchair). After looking at accessible housing and once again being shocked - by the rents wanted - an unexpected home became available to us. (My husband's) mom died, leaving the homestead in (place name) to us. After a long battle of wherefore's, what not's and why not's, we made a decision to move 153 kms away from the security of knowledgeable and skillful doctors and nurses at the IWK. In June 1991, we closed the door, we hoped, for the last time on a rented domain and made the major adjustment of becoming "country hicks" once again after 15 years of living in the city rat race.*
>
> *In our zeal to protect our son and make the transition as easy as we could for (him)we overlooked the needs of our 15 year old daughter who entered grade 9 in a strange high school. She needed us as much or more than (my son) did at this time, but we failed to see it. This would lead to problems later on.*
>
> *The first year we were home (my son) was still able to travel on the school bus to and from school, but the next year was more difficult and I started transporting him - the distance at this time was only 5 kms, to (place name) school.*
>
> *In September 1994 another move - schoolwise. (My son) entered high school in (place name) 35 km away. When I made an inquiry about a special bus coming to pick my son up I was told they couldn't send a bus down there for one student who wasn't even in a wheelchair yet. I finally agreed to transport him to school if they would pay me some gas money.*

Most boys with Duchenne end up in wheelchairs by the time they are 11 years old at the latest. (My son)was now 13 years old and still somewhat mobile. He could walk very slowly while holding on to something or someone. We credit this success to a regime of steroid drugs known as Prednisone which, after much deliberations and agonizing, we had decided to try about 2 years previous to this. (He)was one of the first boys under the medical attention of Dr. (name) to be started on this experimental program. As a result we were subsequently able to tell other parents in our situation it was a success, it had given (my son) 2 extra years of walking.

Move forward to December 27, 1994.

An innocent trip to the mailbox ended (my son's) walking. He slipped in some mud and twisted his ankle. After a trip to the doctor and realizing how serious the sprain was, we were forced to come to grips with the fact that we needed a wheelchair NOW. We had to borrow a wheelchair from the hospital for a few days until we were able to get to (business name) in Halifax where we rented a wheelchair for the next 3 months. It was at this point that we really faced the seriousness of this disease.....13 years old and in a wheelchair.

This leads into the time of our life where we had to make the most adjustments in the shortest time (an extremely stressful 2 years.)

After the 3 month rental of a wheelchair, in March 1995 - 8 years from the time of his diagnosis - (my son) sat in his own wheelchair which is still very much part of his everyday life.

At the time (my son) went into a wheelchair we still had a closet sized bathroom at home and we were able to cope with this for several months as we could still get (him) into the bathroom by supporting and lifting when necessary. In September 1995, our church family realized we were having difficulties getting necessary renovations done to our home in time to accommodate the increasing amount of time (my son) was in his wheelchair. A gospel concert and ham supper raised enough funds to buy materials to enlarge our bathroom and build a ramp from the back door out to where we could transfer (him) to a car. Pastor (name) donated about three weeks of his time to carry out the renovations, helped by Joe when he was not working.

Another major hurdle crossed.

Other hurdles we have traversed in one form or another in the 2 year period (from December 1994 to January 1997) include dealing with medical equipment being moved into our home including a hospital bed, a shower commode chair and a hoya lift. Everything but the shower commode is on long term loan from the Muscular Dystrophy Society. Without these caring, capable folks who have offered not only the loan of necessary medical equipment, partial financing for

Joey's wheelchair, a listening ear and some sound practical advice I don't know what sort of mess we would be in today.

Two years ago we plunged into debt a bit further and purchased a large van that has been partially renovated to give us room to transport (my son) and his chair. Once again the Muscular Distrophy Society loaned us equipment, a set of ramps, so that I am able to push (my son) into the van. Recently a handyman type neighbour of ours helped us install a system of "tie-downs" so now (my son) can stay in his wheelchair and be safely transported in the van without transferring to a seat.

With long term medical needs as is brought about with a disease such as Duchenne muscular dystrophy it certainly takes its toll on every member of the family involved. Physical, mental and emotional stress has led to a bout of major depression for both Joey and myself. I was so concerned for (my son) that I failed to see the signs of complete, absolute exhaustion in myself. One day at the hospital a very understanding and compassionate nurse, (name), realized I was at the end of my rope and had no room left to tie any more knots. I had been dealing with major depression in (my son) who had decided he had enough and had attempted suicide, my husband and I were having serious problems in our marriage, and my 20-year old, unwed daughter called from Ontario with the news "Mom, I'm pregnant." At this point I decided I was stopping my world and getting off. I just couldn't cope anymore at home, at work, in my marriage or in my skin.

(The nurse) asked me if I needed to talk. Just a sympathetic ear but it led to help. The help we got helped us .....over another dozen hurdles.

Looking back over the last 11 years and even before that, there have been so many people who have cared enough to reach out a helping hand. Doctors and nurses at the IWK, doctors and nurses at ESMH, staff and volunteers at the Muscular Dystrophy Association, Children's Wish Foundation, Sheet Harbour Lioness Club, neighbours in (place name) and surrounding communities, my church family, Pastor (name) and (name), Gentlemen at Department of Transportation, and so many others. But most especially I thank my God, Who has given us strength when we had none of our own left, Who continues to guide us with His Loving and merciful grace.

Victories we have had in our battle with muscular dystrophy

1. *Enlarged bathroom, ramp at back door, enlarged bedroom for Joey.*
2. *Van for transportation with ramps and tie-downs.*
3. *Computer from Children's Wish Foundation.*
4. *Outpouring of love and caring and financial help from so many generous people.*

5. Changes in school environment: elevator, bathroom etc.
6. A recognition that many times all we have to do is ask for help.

Also ramp built on credit union, Baptist church and on store in (place name).

Gripes I have noted

1. The government departments that hand out grants or money to help with home renovations have cut offs for income levels at an unrealistic level. It takes a great deal more money to live on when travel to specialists 153 kms away is necessary at least once a month. Also the government departments are guided by the amount of gross income the family has, rather than the take home pay which is close to 1/3 less than gross pay.

Things I am concerned about for the future.......

1. (My son) will need an electric chair soon, within 6 months probably.
2. We need a ramp built on the front of the house.
3. (My son) is not able to go anywhere off the ramp by himself. A system of walkways to the mailbox and to the garden and pigpen would give him some freedom.
4. When he goes into the electric chair we will need a lift for the van.
5. (My son) wants to learn to drive - adjustment necessary to van.
6. Most worrisome fact - Financial funding for all of the above.
7. When do (my husband) and I get to have time to ourselves?
8. Will there be a walkway to the high school from the bus stop?
9. What about his future?

Changes to our family because of Muscular Distrophy

1. Separation of family members - daughter in Ontario
2. Time as a couple very limited, almost non-existent.
3. I'm a full time homemaker as I cannot stretch myself to care for my son, and hold down a job, even part time.
4. now have severe back problems brought on by lifting.
5. Financially on shaky ground.

Outlook for the future

1. More medical needs, more trips to various specialists, more money needed for drugs, equipment, more difficulties in having time as a couple.

Story 2

"Life is like a box of chocolates, you never know what you'll get". Although this is a quote from the movie Forrest Gump, it relates very well to my life, especially as a caregiver.

When my father-in-law died from cancer a few years ago he left my husband and I a beautiful farm, and Oh, yes, my stepmother-in-law, who at that time and still is suffering from Alzheimer's Disease. Since my husband, who is retired, always wanted to return home to Nova Scotia where we were both born, he who grew up there and I who grew up in Ontario decided that we would make the move and would also take care of my mother-in-law until one of her closer family members decided to take care of her. It just didn't seem right to put her in a nursing home at that time, she had just lost her long time companion, whom she was totally devoted for many years. Well, it didn't happen. I guess nobody wanted that responsibility. I became her primary caregiver, which didn't seem to be too bad at first; but caring for someone 24 hours a day, 7 days a week without a break began to take its toll on me. If I didn't get some relief I didn't think I could continue for much longer. Just when I was about my wits end (tired all the time, gained weight and my blood pressure had increased significantly) I noticed an advertisement in the local newspaper for a day care program at a local nursing home. It was called "Take a Brake" and boy did I need a break! It was offered for one day a week from 9:30 a.m. to 3:30 p.m. for a small fee of $15.00.

I can't say enough about what a difference this program has made in my life and in the life of the person I give care to. Even though it is only 6 hours a week it has made a significant difference in both our lives. I only wish there were more days available a person could choose from. Perhaps someone will see the success of this program and things will change and more days will become available.

In the mean time I joined a support group for caregivers, run by (name) and (name) in (place name). This 6 week program was both interesting and informative.

I realize now that we must do everything we can to make our lives as caregivers and the people we care for the best it can be. With an aging population I believe caregiving in the home will become more prevalent and caregivers more important and not just to their families, but to their communities as well.

Story 3

My Experience as a Caregiver

In the mid 1990's I was an employee who qualified for early retirement and decided to accept the package after weighing the circumstances involving family members in need of care. Before I had time to carefully reason what I was getting myself into, I was right back home immediately immersed into all sorts of situations.

Prior to returning home I had a few phone calls from anxious family members wondering when I was coming home. This was before any move to begin packing and before retirement date. I decided to take a month off for all the personal preparation necessary for the change. In retrospect, I should have taken three months.

For almost two decades at my position I lived alone. Prior to this position, I was always coming and going in other positions held, so much so that after being home now for 21 months, my mother and brother still have the attitude that I am not here to stay.

My elderly mother shares her home with my brother (in his fifties) and myself (in my sixties). Adjustment has not come easily. In fact, often I feel as if I'm in the stage of "becoming" a caregiver still. I had no idea that becoming a caregiver would be like bringing a new child into the house.

My brother had returned home to live approximately 20 years ago when all the rest of the family had left. home In his own way, he claims certain territorial rights, so to speak. He has always been my mother's main concern even though she raised a large family. His is the seventh child. When he returned home my father had already died and my mother was living alone and was quite lonely until he came back to live with her after some changes in his life.

When I returned home my mother was already experiencing such signs as memory loss, often never recalling what was said or done and repeatedly asking the same questions, forgetting earlier answers.

Family members live in the neighborhood. Whenever mother positions herself facing the house of a family member, she will ask the same questions repeatedly. She is no longer capable of preparing a complete meal and often does not know if she ate or not., constantly snacking between meals. She likes things to remain the same and prefers not to have visitors outside of the family. She does not easily accept needed changes.

She does not know days of the week and is often disoriented in terms of time. (I post the day and the month right where she can see it, every day and there it stays. Also, she often misplaces things, putting them in strange places and has no recollection of having done so. Other noticeable habits include the hiding of personal items, and arguing,. She has occasional loss of bladder (medication a factor perhaps) and bowel control. She is becoming increasingly immobile and is experiencing personality changes. She greatly fears the onset of darkness and doors which are unlocked as early evening approaches.

A stroke has severely limited my brother's ability to communicate, read and do simple activities; hearing loss renders him extremely boisterous, confused, and emotional. He has frequent loud outbursts, and issues demands at the drop of a hat. He often alienates other family members from taking him out socially or doing things with him. He spends many hours of the day occupying himself in the shed or looking after the grounds.

The decision to become a caretaker is the first of a long list of stresses that can plague anyone who resides in the home. My mother is not ready to give up her independence, even though no one is pressing her to do so. I sometimes resent having all the home care, physical, financial, emotional and never having a break beyond a few hours from home.

I really believe that the caregiver must learn to take charge, but my difficulty comes in learning when to ask for help.

Living in a confined space and knowing that the well-being of two other persons depends on my well-being is a lot of stress; so are living arrangement, re-arranged schedule and limited privacy. I learn to distance myself from the pressure of caregiving by going out about 4 or 5 times a week or disappearing upstairs with my mother thinking I am out.

Family members, apart from one, do not help as much as they could. Everyone is too busy. I thank God for the one willing helper. No one ever offers to stay overnight, which prevents my going away. Regrettably I believe that I am practically the only person who can do what I am doing and am reluctant to solicit the help of others. I may always have to be here and that's a concern I have.

I'll do what I can to keep my mother away from institutional care. She has been a good parent and I like to respond in kind.

Story 4

On June 25, 1997 our family increased by one, but not in the usual way.

My husband and I had been married for almost twenty-six years. During this time we had raised three sons. They ranged in age from nineteen to twenty-three. Our two eldest were still living at home, but were working and earning their own way. Our youngest had been a concern since he was born. He had suffered a stroke while I was pregnant with him. The left side of his body was affected and he suffers from epilepsy. He is both mentally and physically challenged. We had struggled with the school system for many years to see that he got a good education and he was finally graduating from grade twelve. Our oldest and youngest were both enrolled at (school name) for September. It looked like my husband and I would enjoy some peace and freedom. It was not meant to be.

My husband's brother, (name) , had suffered a stroke in 1991. The stroke was caused by alcohol. The right side of his body was paralyzed and he was mostly confined to a wheel chair. At the time this occurred he was married and had three grown children. His wife left him in July 1992. His youngest daughter and her family moved in to take care of him. Over the next five years there were many problems, mainly with the daughter's husband and (my brother in-law). At the end of May, 1997, (my niece) and her family decided to leave.

(My brother-in-law) came to my husband and asked if we could move in to take care of him. It would be a hardship for him and for us for (him) to move into our home. We had a split level house and it would take new finances to have it equipped for a disabled person. Together, with out children, we made the decision to move.

(My niece) and her family were moving out at the end of June. It didn't leave much time to pack up and make arrangements to rent our house. This all happened a few weeks after my mother-in-law unexpectedly died. I had also lost my father and father-in-law within a year of each other, less than two years before. It was a very traumatic time for everyone. With all the turmoil surrounding the move and my mother-in-law's death there was also (my son's) graduation. This was supposed to be a happy time in his life, but we weren't able to fully give our attention to his achievement.

In the first week of June, my husband and I met with (my niece) and her husband to discuss what bills (my brother-in-law) had and how they were paid. We also discussed (his) care. We were responsible for seeing that his bills were paid. He received a disability pension and $350.00 a month from Community Services for home care. He also took medications and we were responsible for monitoring that as well. We were also expected to have his meals ready for him. It seemed like we were going to care for another child. At the time I was teaching and my *husband was fishing. We both had concerns, but decided that we could deal with them.*

(My brother-in-law) stated that whoever took care of him would inherit his home as that was all he could offer. It came as a shock to him to discover that he did not have title to his home. A quick claim deed was signed in March of 1992 by him and his ex-wife that deeded the property to (my niece). (My brother-in-law) was under the impression that he had signed a will. At the same time it was also discovered that (my niece) and her husband had taken advantage of the trust (my brother-in-law) had placed in them to pay bills and put money in the bank for his mortgage payments. The bills were not paid and there was $1,200.00 missing from his bank account. Emotions became very intense. (My niece) and her father could not settle things. (My brother-in-law) had the RCMP involved. This caused angry feelings between (him) and his children. (He) also hired a lawyer to see if he can get the title to his home. Now my husband and I find ourselves in the middle of (my brother-in-law's) family dispute. His children blame us for all the turmoil.

In the midst of this I still work three days a week, see to all of (my brother-in-law's) physical needs, pay his bills, do his banking and take him to doctor's appointments, etc.

This has been a learning experience for our whole family. With the help of his doctor and Community Services we have managed to cope. The rewards outweigh the loss of privacy and freedom. Some of the rewards are seeing (my brother-in-law) do his exercises and talk more. I hope that he feels that he has people who he can trust to take care of his needs.

(My brother-in-law) is treated with respect, dignity and patience. On June 25, 1997, we became the caretakers of a 54 year old man, who is now a member of the family.