

Coping as a Rural Caregiver: The Impact of Health Care Reforms on Rural Women Informal Caregivers

Executive Summary

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INTRODUCTION

Healthcare in rural Saskatchewan is rapidly changing. Many rural communities are losing their hospitals, long-term care facilities and, in some cases, primary care services. Care of the chronically ill or disabled is being deinstitutionalized. Respite or physical therapy services are scarce or becoming centralized and more difficult to access. The numbers of rural informal caregivers are increasing, while insecurity regarding medicare and the restructuring of health services is intensifying (Rosenthal, 1994).

Health care restructuring has been a tug-of-war between maintaining the five pillars of medicare (accessibility, portability, universality, comprehensiveness, and public administration) and controlling health care costs (Rosenburg and James, 1994; Haislmaier, 1991). This struggle has resulted in a shift from institutional to community and home care for acute and chronic conditions (Armstrong and Armstrong, 1996). In Saskatchewan, efforts to control health care expenditures have led to hospital closures, fewer acute care beds in rural areas (Braden, 1998), reduced numbers of doctors and nurses (Eisler, 1996), an out-migration of medical specialists, and fewer beds in long-term care institutions (HSURC, 1994). At the same time, additional funding has gone to home care (HSURC, 1998; Kyle, 1998).

There has been a shift to community care for persons with disabilities and reduced spending for long-term care institutions for the aged. There has been a shift from hospital to home care, with increased out-patient and day surgeries, early release programs, and reduced long-term care in hospitals (Braden, 1998) With these changes, we have seen a shift from care provided by skilled health professionals to caregiving by less-skilled family and home care workers (Armstrong, 1997).

This shift from institutional to community care appears to be about *where* health services are offered--in hospitals or homes. In fact, it is about much more. It represents a profound shift in philosophy away from the principles of medicare and toward the privatization of health care. Since home care does not fall under the umbrella of the *Canada Health Act*, universality is compromised. In Saskatchewan, regional health districts are responsible for home care services, and the range of services and eligibility policies vary among the districts. Some services that would be available by rights to hospital patients under the *Canada Health Act* must be purchased by persons receiving care at home (Armstrong and Armstrong, 1996).

Health care restructuring and regionalization were promoted as means of increasing accountability in the health care system by making it more democratic (Hurley *et al.*, 1993), yet family caregivers, as a group, are not represented on health district boards, and changes in the health system are often made without their participation. Accountability works more on the consumer-based model, wherein caregivers choose which services to purchase, but have little say in determining which services are available.

Policy-makers are introducing rapid changes to the health system, yet little is known about their impacts on rural informal caregivers. Policies appear to be based on myths and assumptions about rural women, families and communities.

Rural women informal caregivers are virtually invisible to many policy-makers, because caregiving for ill and disabled people is considered an extension of women's domestic responsibilities (Henderson, 1998). The devolution of care to wives, mothers, daughters, and sisters is based on "traditional" ideas that women's employment is non-existent, unessential, or part-time (Pless, 1984; Armstrong and Armstrong, 1996). Women are assumed to be available for caregiving, regardless of their age, health, or existing responsibilities. As a result, caregivers are seeing their workloads increase, often with little recognition, little training, no financial compensation, no protection in case of injury, and no workers' benefits. (ICUW, 1997).

It is assumed that rural families have strong ties across generations, that adult children live in the area, and that they are available to care for aging parents. Today few families have more than one or two relatives residing in the same community. Like their urban counterparts, rural families are small and highly mobile. Family support for the ill or aging is most often undertaken by one family member--usually female (Montgomery and Hirshorn, 1991; Barris, 1998). These women may be uneasy or unhappy about their role as caregivers. They may feel inadequate, guilty, or even unwilling to provide care, but see little choice (Braithwaite, 1996). When demand for care is intense, family relations can become strained as caregivers are overwhelmed by exhaustion and resentment (ICUW, 1997).

Rural families are thought of as propertied, financially stable and homogenous. However, inequalities are increasing in rural areas and many families find themselves financially strapped (Ames *et al.*, 1994). Rural people often lack income security when faced with long-term illness or disability (Black *et al.*, 1993). Many rural women caregivers have limited income due to retirement or lack of paid employment (Mui and Morrow-Howell, 1993). Policy-makers often overlook the financial situation of rural families, assume the cost of living to be low in rural areas, and ignore hidden costs like transportation. (Richardson, 1988).

Rural places are considered idyllic, yet isolation, lack of public transportation, and the limited social resources of small communities can place intolerable stresses on those giving and receiving care (Richardson, 1988). Poor quality housing and insufficient health and social services characterize many rural communities. Distance makes access to services more difficult and adversely affects rural women's ability to provide care (Giarchi, 1990).

Rural communities are thought of as close-knit and neighborly, yet stress from isolation is a serious concern (Richardson, 1988). Geographic dispersal of the population means that people risk isolation from neighbors and services. Rural depopulation represents a decline in social resources; fewer people are available as social supports. Inadequate transportation, fewer family supports, and a lack of daycare and respite facilities limit

caregivers' access to assistance or relief (Giarchi, 1990). While caregivers' experiences vary, isolation and lack of social support can affect their well-being.

Canada's population is aging, particularly in rural areas. In 1991, nearly one-third of Canadians over 65 lived in rural areas (CMHC, 1991; Hendryx, 1993). Rural centres have higher proportions of elderly people and higher rates of long-term disability and chronic illness than cities (Wilkins, 1992). It is estimated that 80% of elder care is provided by family members, primarily women (Barris, 1998). In 1997, Statistics Canada reported that nearly three million Canadians were looking after someone with chronic health problems. As the population continues to age, Canadians will have to care for older family members, and caregivers themselves will be older.

The differences between urban and rural places, and the challenges faced by rural informal caregivers need to be taken seriously in the formulation of health policies. Yet very little is known about rural informal caregivers in Saskatchewan. What are their social and economic situations? What difficulties do they experience as caregivers? What resources and supports are available? What solutions do they see?

METHODOLOGY

The Rural Women Informal Caregivers Study focused on the following:

- How provincial and federal health reforms are affecting the economic, social, psychological and physical well-being of women caregivers in rural communities.
- How the impact of health reforms on these rural women caregivers is further magnified by the lack of formal and/or informal social supports.
- How factors such as income, education, social status and employment affect the type of difficulties experienced by these caregivers.
- The type of formal and/or informal supports rural women caregivers need and how these needs can be met through policy changes and community participation.

The North Valley Health District was chosen as the site of the study because the area was well-defined and caregivers in the district had the potential to access the same number and type of health care services. The area was made up of smaller communities and therefore considered rural. The district was close enough to Regina that day trips could be made by the researchers, but far enough that caregivers in the area were not able to access city services easily. The district had health care representatives willing to cooperate in the study.

Names of informal caregivers were solicited from a variety of local organizations and community groups in order to create a list of sixty potential interviewees. The caregivers had to be women residing in the North Valley Health District and providing care to a person also residing in the district. They had to be actively caregiving for a child, spouse or parent, at the time of the study.

Individual interviews, using a structured questionnaire, were conducted with 53 women between June and October 1998. Most interviews were conducted in the caregiver's home. Six interviews were carried out in public restaurants chosen by the caregiver. The interviews lasted between 45 minutes and four hours. Most caregivers made arrangements for the care-receivers to be elsewhere during the interviews or resting. Those care-receivers who were present often interrupted to ask questions or receive help, but did not actively participate in the interview. Excerpts from interviews are presented in italics.

THE NORTH VALLEY HEALTH DISTRICT

The North Valley Health District is one of over thirty health districts created since 1992, when the Government of Saskatchewan began to restructure the provincial health care system. Under *The Health Districts Act*, district health boards have the authority to provide and evaluate health services, perform needs assessments, and promote health and "wellness" for members of their district (Saskatchewan Health, 1995). Health boards are comprised of appointed and elected members.

The long and narrow North Valley Health District is centered in Melville. With its most eastern extent the Manitoba border, it includes the towns of Ituna, Esterhazy, Atwater, Bangor, Birds Point, Dubuc, Duff, Fenwood, Gerald, Goodeve, Grayson, Hubbard, Killaly, Melville Beach, Neudorf, Spy Hill, Stockholm, Tantallon, West End and Yarbo. According to Saskatchewan Health (1998), the North Valley Health District has 14,992 residents. This is a 3% population decrease from 1996 (North Valley Health District Report 1996-1997).

Although the district overall is experiencing depopulation, the smaller centres are losing the most people per capita due to farm service centre consolidation, rapidly increasing farm sizes, and the loss of essential services (i.e., postal outlets, banks, hospitals). Melville, the largest centre in the North Valley Health District, has also experienced an out-migration of people. However, some functions previously performed in smaller centres have become centralized in Melville, and the rate of depopulation there has been less dramatic. In the health sector, smaller centres are losing medical facilities to larger towns, and larger towns are losing facilities for advanced procedures to even larger places. Some communities have no local physician care.

Health care reform in the North Valley Health District has involved a reorientation of services, following a government mandate to make "substantial changes in the provision of health services including an increased emphasis on disease and injury prevention, healthy lifestyles and community-based health programs, and increased coordination and integration of health services to provide a more responsive and efficient health system" (Saskatchewan Health, 1995). This process has resulted in hospital beds closures and a 3.4% increase in the out-migration of district residents for acute care services between 1993/94 and 1995/96 (North Valley Health District, 1996/97). In addition, there has been a renewed emphasis on outpatient and home care services. At present the North Valley Health District has two hospitals located in Melville and Esterhazy, with a total of 68 beds, a community health centre located in Neudorf, two nursing homes located in Melville and Esterhazy and one health centre integrated with a long term care facility located in Ituna. According to Marian Terlesky, of the North Valley Health District, there are currently 240 nursing home beds in the district. Home care services are provided throughout the district with approximately 631 people receiving these services (April 1997). Adult wellness programs are available in the communities of Esterhazy, Ituna and Melville. In 1996/97, these three wellness clinics were used 2,536 times by 83 clients. Wellness clinics are also held in eight communities with a total clinic attendance of 1,242 in 1996/97 (North Valley Health District Report 1996-1997).

The demographic processes affecting rural Saskatchewan are particularly pronounced in this district. Close to 22% of the people residing in the North Valley Health District are 65 years or older--about 7% above the provincial average (Saskatchewan Health, 1998). People in their middle years represent approximately 29% of the district, compared to the provincial average of 27%. In contrast, people aged 0 to 19 years make up only 26% of the district, 4% below the provincial average; while people aged 20 to 39 years comprise less than 24% of the district, compared to 29% of the provincial average. These figures indicate a continual declining population base, with a concomitant shrinkage of services. In short, to a greater degree than one finds in the overall population, this district will have fewer people and resources to care for an aging population, at least for the next two decades.

STUDY FINDINGS

WHO ARE THE CAREGIVERS?

- Caregivers in this study were between 28 and 87 years, and half were over 60 years old.
- Many of the women interviewed have less than a grade 12 education. In general, the younger the caregiver, the higher the level of education.
- Of the 49 caregivers who offered income information, 47% have a gross family income of less than \$30,000. Of these, more than half have incomes below \$15,000. One reason for these low incomes is that nearly two-thirds of the caregivers do not work outside the home.
- Over three-quarters of the caregivers in this study live in small towns and communities, while the rest remain on-farm.
- Eleven of the women interviewed are caregiving for one person besides the primary care-receiver, while an additional five are caregiving for two other people.
- Nineteen of the women interviewed are mothers caregiving for ill or disabled children, 14 are daughters caregiving for parents, and 20 are wives caregiving for husbands.
- Five caregivers have been caregiving for more than 20 years, with one caring for 35 years. Among those who live with their care-receivers, the median time caregiving is 7.5 years.

WHO IS RECEIVING INFORMAL CARE?

- This study included care-receivers between two and 98 years old, with the median age being 70.
- Thirty-four care-receivers were male while 19 were female. A majority of the male care-receivers were married, while all but one of the female care-receivers were unmarried.
- 60% of the care-receivers live in the same home as the caregiver, while 40% live in the same community as the caregiver.
- Of those care-receivers who do not live with the caregiver, 57% live in their own home, 33% live in a care home⁽¹⁾ and 10% live in a group home.
- Two-thirds of the care-receivers have more than one medical problem--40% have three disabilities or medical problems, while an additional 19% have four problems.

HOW THE CAREGIVER ROLE EVOLVED

Almost all the women in our study took on the role as caregiver, in part, because of a lack of family alternatives. Fourteen women said that the care-receiver had no other family members available to care for them either because they lived too far away (11), or because they had all passed away (3). Eight of the women indicated that the lack of family alternatives was the result of family dynamics--five caregivers stated that the care-

receiver had family in the same community but that they were unwilling to help due to the care-receiver's history of alcoholism, abuse and neglect.

"I have not chosen to become a caregiver. I've been stuck with the job because no one else wants it."

TASKS PERFORMED BY CAREGIVERS

- Caregivers in this study performed many different tasks: laundry, household cleaning, meal preparation, grocery shopping, bathing, routine bathroom, bladder function, changing pads, bowel function, incontinence, shaving, brushing teeth, supervision, administering medication orally, administering medication by needle, administering medication by other means, physiotherapy/exercise, decision-making, acting as a confidante, ordering medication, purchasing medication, driving to doctor/physiotherapy appointments.
- While 15% of the caregivers perform five different tasks or less, 51% perform six to ten different tasks and 34% perform 11 to 16 different tasks.
- Many caregivers who help the care-receiver make decisions (46), supervise the care-receiver (35), and act as a confidante (30) stated that these caregiving tasks are done "all the time."

DIFFICULT TASKS FOR CAREGIVERS

- 41.5% of the caregivers identified dealing with frustration as a difficult caregiving task.

"Sometimes it's like having a baby except you know they are not going to grow out of the helpless stage they are in...I don't find the physical activities, such as lifting him, demanding. Instead the repetitiveness of the tasks is what I find frustrating. Having to do the same tasks over and over again and always at a specific time and place is almost maddening."

- 30% said dealing with the care-receiver's behaviour is a difficult caregiving task.

"I think my biggest problem when it comes to caregiving for my husband is giving him a bath. It's not actually getting him into and out of the tub that is difficult, but persuading him to actually have a bath. My husband argues with me over this issue and sometimes threatens to hit me. I know his reaction is a result of the illness, but it's really hard to deal with. I feel I have no control sometimes."

"My disabled son was born 35 years ago...Today I am 75 years old and a widow. I'm finding caregiving for my child to be more stressful than it used to be...The most difficult part of taking care of my son is his mood

swings. Sometimes he can be really stubborn, while at other times he just outrightly refuses to talk to me."

- Most caregivers make decisions, or help the care-receiver make decisions on a regular and ongoing basis. Many find this a difficult part of caregiving, which gives rise to feelings of guilt and uncertainty.
- Several caregivers felt it was difficult being the care-receiver's only confidante. Some felt that this situation was unhealthy for themselves and the person receiving care.
- Several caregivers described the difficulty of dealing with feelings of guilt--guilt over giving birth to a child with disabilities, guilt over being healthy when the other person is ill, guilt over not understanding the person's illness, guilt over not making the right choices about medications, doctors, or the use of health care facilities.

HOW COULD CAREGIVING TASKS BE MADE LESS DIFFICULT?

- Caregivers feel that having strong support from the community and family members would make their caregiving tasks easier.
- Sadly, 30% of the caregivers believe there is nothing that can make their caregiving tasks less difficult.

CAREGIVING SUPPORT FROM FAMILY

- Although 26 caregivers reported receiving caregiving help from other family members, 27 did not. Older caregivers were more likely to report not receiving help from family.
- Caregivers not receiving help from family are often caring for very old people.
- 67% of all caregivers receiving help from family are being helped by at least two different family members.
- Caregivers' children and siblings were the family members most frequently identified as helping with caregiving duties.
- Supervising the care-receiver, preparing meals and cleaning house were the tasks most often performed by other family members.

CAREGIVING SUPPORT FROM FRIENDS AND THE CHURCH

- A little over a third of the caregivers received help from friends with their caregiving tasks.
- Friends primarily offered supervisory or visiting assistance to the caregivers.
- A lack of caregiving help from family did not result in more caregiving help from friends.
- The church provides little support to caregivers. Thirteen caregivers said they receive caregiving help from the church, while 36 do not.
- Ten caregivers not receiving help from the church discussed their disappointment with the churches' indifference to their situations.

COMMUNITY AND NORTH VALLEY HEALTH DISTRICT SUPPORTS

- Caregivers identified a wide range of health district services as community supports but few were accessing more than one of these services.
- Caregivers reported using home care, respite care, care homes, hospital and doctor services.
- Approximately 40% of the caregivers interviewed receive home care.
- In 62% of the home care cases, the medical profession initiated the services.
- Caregivers primarily receive help from home care with general household tasks. Fifteen receive light household cleaning; seven receive help with laundry; and seven have meals prepared or meals-on-wheels arranged.
- When caregivers were asked if their questions about home care services are being answered to their satisfaction, 85.7% said "yes." However, when asked if they felt they had a say in the type and frequency of home care being provided, only 57.1% said "yes."
- Caregivers feel that having more home care workers available (5), more knowledgeable home care workers (5), and not so many different home care workers (5) would make home care more attractive to people.
- 25 caregivers believe that community support should focus on maintaining hospital and clinic services while 24 caregivers believe that community support should focus on expanding group and care homes.
- Four caregivers feel home care services are "great just the way they are," but three feel home care is "useless" and wouldn't use it.

IMPACTS ON CAREGIVERS

Although informal family caregivers are not personally responsible for the philosophical and structural shifts in health care reform, they are undeniably affected by them. When the ill and disabled are released into the community, it is the family that becomes primarily responsible for their care (Charters, 1995; Montgomery and Hirshorn, 1991). Family caregivers today are expected to perform difficult caregiving tasks--including administering medications, assisting with physiotherapy exercises and performing medical procedures--with little or no training. In addition, caregivers are finding themselves caring for increasingly longer periods of time and often for more than one care-receiver (Henderson, 1998; Merrill, 1993).

Evolving health policies and shifting demographics are affecting all caregivers. However, the rural informal family caregivers find themselves in the most precarious position, as they are being asked to provide care at a time when their social and structural supports have become exhausted, depleted or non-existent. Changes to the health care system are not taking place within a bubble. As rural family caregivers attempt to work within the health care system, they are also being forced to address issues related to public transportation (Richardson, 1988), rural depopulation, a loss of health and welfare services, dwindling social resources, isolation (Henley *et al.*, 1998), and poor quality of housing (Giarchi, 1990). In addition, rural caregivers are burdened by their own health-related issues as they tend to be older (Campbell *et al.*, 1998), and have higher rates of long-term disability and chronic illnesses than their urban counterparts (Wilkins, 1992).

Recent studies show that 80% of all family caregiving is done by women (Barris, 1998, Franklin, Ames and King, 1994) and caregiving continues to be seen as an extension of women's domestic responsibilities (Henderson, 1998). Rural women informal caregivers find themselves in a difficult situation. These women have to cope not only with the restructuring of their health care system but also of their communities. This study reveals that these changes are affecting caregivers' social lives, their work, and their health.

THE CAREGIVER'S SOCIAL LIFE

Caregivers' social lives are limited by their caregiving duties. Six of the women interviewed have stopped participating in any social activities since becoming a caregiver, while 11 others identified activities they do alone as their only social activities since becoming caregivers. Only 13 caregivers stated they are happy with their current level of involvement in social/ extracurricular activities. Of the 40 caregivers who are not happy with their level of social/extracurricular activities, 33 directly connected the burdens of caregiving to their reasons for not participating in more activities. Seventeen of the caregivers said they could not justify spending the money or taking the time away from the care-receiver to get involved in more social activities. With limited financial and social resources, the caregivers' desire for more social activities was not seen as a priority. Eight caregivers said that although they could probably find the time and money to get involved in more activities, they were just so tired from caregiving that they needed to rest. Eight caregivers said that they would like to get involved in more

social/extracurricular activities, but it is difficult to find a qualified care provider and too stressful to have the care-receiver accompany them.

"I find it really hard to find appropriate care for my daughter. There are few older people in my community who are interested in caring for a disabled child and younger people, such as high school students, usually do not have the patience or ability to cope with my daughter's disability."

Long caregiving hours and a lack of family support limit caregiver involvement in social activities. Caregivers who spent more hours per week with the care-receiver were more likely to say they were dissatisfied with their level of social activities. Of the 26 caregivers who self-reported spending 50 hours or less per week with the care-receiver, only 35% were interested in being involved in more social activities. In comparison, 70% of the 27 caregivers who self-reported spending 51 hours or more per week with the care-receiver indicated they would like to be involved in more social activities.

Caregivers who do not receive family support were more likely to report being dissatisfied with their level of social activities. Of the 26 caregivers who are not receiving caregiving help from family members, 19 or 73% reported wanting to be involved in more social activities. Meanwhile, only nine of the 27 caregivers who do receive family help with caregiving indicated that they would like to be involved in more caregiving activities. Families not only supervise the care-receiver so the caregiver can be involved in social activities, but also participate in the activity with the caregiver. In many instances, it is a family member who insists the caregiver get out of the house for a while—dragging her out for a coffee or a walk. To further support this finding, over 50% of the caregivers who feel something can be done to make their caregiving duties easier, reported that having stronger family and community support would be a significant help.

CAREGIVING AND WORK OUTSIDE THE HOME

Older caregivers took early retirement to perform their caregiving duties. Eight of the sixteen caregivers who are retired from the paid workforce, stated that they had taken their caregiving role into account when deciding to retire.

Six women retired within a year of becoming a caregiver and directly related their retirement to the demands of caregiving which increased their stress or led to a deterioration of their own health.

Caregivers are adjusting their work life to accommodate their caregiving duties. Sixty-seven percent of the caregivers currently in the workforce have had to make workplace adjustments since becoming a caregiver. Three of the caregivers have had to change jobs in order to reduce their hours of work or to be in a flexible enough position to accommodate their caregiving duties. Seven of the caregivers are working at the same job, but have had to reduce their hours to make caregiving easier. Two caregivers have had to increase their hours of work in order to make more money, to support the family's added needs.

"It's hard to keep on top of work and caregiving responsibilities. Working less would make things easier but that's impossible because we really need the money right now."

Combining work and caregiving often means less sleep and no social life. A majority of the caregivers with paid work outside the home stated that balancing work and caregiving resulted in not having enough time for a social life or not getting enough rest. These women said that when juggling caregiving, employment and their own personal lives, it is most often their personal lives that suffer.

THE HEALTH OF INFORMAL CAREGIVERS

Women are reporting that their health has deteriorated since taking on the caregiver role. Two-thirds of the caregivers in this study consider themselves to be healthy. Close to half of all the caregivers interviewed reported that their health had deteriorated since taking on the caregiver role. It is interesting to note that some of the caregivers who identified themselves as healthy still feel that their health has deteriorated since they started caregiving. These caregivers reported suffering from more stress headaches, chronic back pain, depression and emotional and physical exhaustion since they began caregiving. As caregivers are compelled to care for more than one care-receiver over their lifetime and for longer periods of time, we can anticipate seeing greater numbers of stress related illnesses develop in caregivers.

How a caregiver reports her health is directly correlated to her level of family support and employment outside the home. Caregivers who do not consider themselves healthy are very likely to feel their health has deteriorated since they started caregiving. Remarkably, age and income seem to have very little effect on whether caregivers say they have become less healthy--although young healthy caregivers are slightly more likely to report that they have experienced deteriorating health. People with higher levels of education are more likely to consider themselves healthy, yet are also slightly more likely to say their health has deteriorated since they began caregiving.

The most significant variables to explain both whether the caregiver considers herself to be healthy and whether her health is staying the same or deteriorating are family help and outside employment. Caregivers who are employed outside the home are much more likely to consider themselves as healthy and are unlikely to report their health as deteriorating since they started caregiving for a family member. In contrast, caregivers who do not work outside the home are both more likely to evaluate their health as poor and to feel it has deteriorated.

A large number of caregivers who do not consider themselves healthy receive no assistance from family members with their caregiving duties. Meanwhile, caregivers who do receive help are more likely to consider themselves as healthy, and are also less likely to feel that their health is deteriorating.

POLICY IMPLICATIONS

This study was initiated to give rural women informal caregivers a forum to discuss their needs. Based on their experiences and suggestions, we have highlighted significant areas of concern to be addressed in health policy.

1. **Recognize that rural caregivers need social and emotional supports.** Although caregivers acknowledged the need to have physical supports, such as wheelchairs or hand railings, they were much more likely to identify a lack of emotional and social supports as making their caregiving duties difficult. Caregivers reported frustration, guilt, isolation and loneliness. When asked how caregiving could be made easier, they emphasized stronger family and community supports.
2. **Recognize that family supports are often not available to the caregiver.** Caregivers who are not receiving family support often do not have family available in the community. As families continue to be more mobile and young people move to urban centres to find employment, fewer caregivers are going to have available family supports. Today, families are not only moving to other communities, but to other provinces, countries and continents. Policy-makers need to address this trend and recognize that as health care moves into the community, family supports are moving out.
3. **Improve access to community services.** Caregivers using home and respite care, are generally happy with the services. However, half of those interviewed did not use these services. When asked why, most responded that neither they nor the care-receiver were comfortable with someone else being in their home or offering personal care. Caregivers not using home care tended to favor institutional care. Not all caregivers are comfortable with home care, and alternative services need to be offered, such as government-funded level one and two home care.
4. **Adequately fund support services and institutional care in rural communities.** Caregivers receiving home care and accessing respite care feel that financial support for these services is needed. Caregivers feel that more dollars need to go into home care to allow for additional workers and more caregiving time. Caregivers who use respite services believe more respite beds are needed in the district.
5. **Provide information on available services.** Caregivers need more detailed information on available services and someone to discuss the services with them privately. Many of the caregivers stated that what they knew about health care services in their district was based on second-hand knowledge and not necessarily on fact.
6. **Recognize that rural caregivers tend to be older and have their own health problems.** Older caregivers feel that the shift to community health care has not addressed the fact that in rural communities the population is significantly older than in urban centres, and therefore rural caregiving is being done by older--and usually less healthy--people. These caregivers want policy-makers to take into account age limitations, physical and mental health, limited financial resources and transportation capabilities.

7. **Acknowledge that caregiving is work and provide financial remuneration for it.** Caregivers do not feel that their work is being valued by society in general and by government and policy-makers specifically. Many of the caregivers stated that as health care becomes increasingly linked to one's private home, it will become invisible to the public. In order to recognize the work being done by informal caregivers in the new community-based health care system, many caregivers believe that a monetary value needs to be placed on their work.

"If I was not doing the caregiving for free, someone else would have to do it for a wage!"

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Endnote:

1. When referring to care homes we are talking about long-term care facilities that are government-funded.