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## Rural families caring for a relative with dementia: barriers to use of formal services

Debra G. Morgan<sup>a,\*</sup>, Karen M. Semchuk<sup>b</sup>, Norma J. Stewart<sup>b</sup>, Carl D'Arcy<sup>c</sup>

<sup>a</sup> Centre for Agricultural Medicine, Wing 3E, Royal University Hospital, University of Saskatchewan, 103 Hospital Drive, Saskatoon, Saskatchewan, Canada S7N 0W8

<sup>b</sup> College of Nursing, University of Saskatchewan, Saskatoon, Saskatchewan, Canada S7N 5E5

<sup>c</sup> Applied Research/Psychiatry, University of Saskatchewan, Saskatoon, Saskatchewan, Canada S7N 5E5

### Abstract

Planning for the care of increasing numbers of elderly persons with dementia has become an urgent health services concern in Canada and elsewhere, yet little is known about the challenges of providing appropriate dementia care in rural areas. A community-based approach was used to obtain input from decision-makers and others to develop the objectives and design for a study of rural dementia care in the province of Saskatchewan, Canada. The resulting study design, which used both qualitative and quantitative methods, was then pilot tested in one rural health district (16,000 km<sup>2</sup>, population 20,000). This paper describes the study development process and reports selected findings from focus groups conducted with home care staff and family members, focussing on the theme of low use of formal supportive services such as home care and support groups by family caregivers. Participants identified eight barriers to the use of formal services, described consequences of low service use, and suggested strategies for addressing this concern. © 2002 Elsevier Science Ltd. All rights reserved.

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In Canada and elsewhere, planning for the care of increasing numbers of seniors with dementia has become an urgent health services concern. Although rural elderly prefer to stay in their communities, little is known about the challenges of providing appropriate dementia care in rural areas. Developing uniquely rural solutions to these challenges requires an accurate understanding of rural dementia care as it currently exists. This paper describes the community-based process and pilot project that were used to develop a study of rural dementia care in the western Canadian province of Saskatchewan, and reports findings related to barriers to use of formal supportive services by families providing care in the home for a relative with dementia.

### Background

Dementia, most commonly caused by Alzheimer disease, is characterized by gradual deterioration of memory, language function, other intellectual abilities, and general competence (American Psychiatric Association, 1994). The major known risk factor for dementia is age, with an estimated prevalence of 34.5% among the old-old (85 years and over), compared to 2.4% among those aged 65 to 74 years (The Canadian Study of Health & Aging [CSHA] Working Group, 1994). Statistics presented at the First World Alzheimer's Conference held in Washington, DC, in July 2000, predicted an increase in the incidence of dementia in the industrialized world from 13.5 million persons currently affected to 36.7 million in 2050, with even greater increases predicted for developing nations (Vale, 2000). The prevalence of dementia in Canada is expected to increase from approximately 364,000 persons in 2000 to

\*Corresponding author. Tel.: +1-306-966-7905; fax: +1-306-966-8799.

E-mail address: morgand@sask.usask.ca (D.G. Morgan).

over 750,000 persons by 2030, with roughly half of the cases living in the community (CSHA Working Group). The increasing number of seniors choosing to stay in their rural communities (Canada Mortgage & Housing, 1991) raises questions about the capacity of those communities to provide specialized dementia services. Studies conducted in the United States indicate that health and human services for the rural elderly are less accessible, more limited in variety, and fewer in number than in urban areas (Coward, Netzer, & Peek, 1996; Krout, 1994). Obstacles to providing specialized mental health services for the rural elderly include low population density, longer distances to travel, and lack of access to personnel with advanced training (Abraham, Buckwalter, Neese, & Fox, 1994; Bushy, 1994).

The “reluctance” of family caregivers to use formal services has been described in earlier studies (Connell, Kole, Avey, Benedict, & Gilman, 1996; Coward, Cutler, & Mullens, 1990). Underutilization or low use of services is defined as the gap or discrepancy between the need for and acceptance of formal services (Gräsel, 1997; Rudin, 1994). With respect to dementia care, little is known about factors influencing caregivers’ decisions regarding use of formal services. Gräsel (1997) found no relationship between service use and need, defined as level of subjective burden and somatic symptoms. Rudin (1994) reviewed the existing research and practice-based literature and found no studies on caregiver attitudes regarding utilization of services designed to provide temporary relief of caregiving responsibilities. Although Rudin was able to identify four categories of factors that may influence utilization of respite services (availability, accessibility, quality or hospitality, and usefulness), she concluded that one of the “missing links” in improving services for caregivers of persons with dementia is understanding why they choose not to use services (Rudin, 1994, p. 101).

Although family members are the primary source of assistance for rural elders, it is unclear whether this reliance is because of strong informal networks, inadequate formal services, or reluctance to accept help from formal service providers. Earlier research suggests that older people turn to formal services when their needs exceed the capacity of their informal networks (Stoller & Pugliesi, 1988), but this pattern appears to be different for rural elderly, who are more likely to receive help exclusively from family members (Coward et al., 1990). Coward et al. explored residential differences in use of formal and informal services by elderly persons in a large ( $N = 3761$ ) national survey in the United States and found that severely impaired elders residing in nonmetropolitan communities were less likely than their metropolitan counterparts to receive aid from a formal provider, and were significantly more likely to receive assistance from informal helpers only. While the data provided no insight into *why* severely impaired urban

elders would be more likely to include formal helpers in their networks, the authors suggest that this finding may reflect lower availability of formal services in small towns and rural communities, or the “often talked about, but seldom empirically documented reluctance of rural elders to use formal services” (Coward et al., 1990, p. 48). Findings of several studies suggest that rural persons prefer to use informal sources of help to deal with health problems (Collins, Stommel, King, & Given, 1991; Long & Weinert, 1989; Weinert & Long, 1987) and others have documented a lower availability of services for persons with dementia and their families in rural compared to urban areas (McCabe, Sand, Yeaworth, & Nieveen, 1995; Shope et al., 1993). The independence and self-reliance of those living in rural areas have been associated with delayed help-seeking (Long & Weinert, 1989; Stoller, 1996). Connell et al. (1996) identified both attitudinal and structural barriers to service delivery and utilization of dementia care services in rural Michigan. In Florida, rural elderly were more likely than their urban counterparts to identify barriers to service use, including lack of awareness, transportation limitations, and perceived rigid eligibility standards (Schoenberg & Coward, 1998).

Further research is needed to understand the barriers to the use of formal community-based services by rural family caregivers, including those caring for a relative with dementia (Collins et al., 1991; Coward et al., 1990; Coyne, 1991; Keefover et al., 1996; Magilvy, 1996). In the present study, the theme of underutilization of formal services by families caring for a relative with dementia in a rural health district in Canada emerged spontaneously in focus groups with home care staff. Both staff and family caregivers identified barriers to the use of formal services in the community, as well as perceived consequences of failure to use services earlier.

### Study development

This project used a multi-stage community-based approach aimed at facilitating the planning of a larger study of rural dementia care. Partnerships between service providers and researchers are essential in addressing current challenges in providing long-term care for rural elders (Coward et al., 1996). Community-based approaches, founded on the premise that the community has insights about the problem and possible solutions, emphasize collaboration, a reciprocal education process, and an emphasis on taking action on the issue (Green et al., 1995). The researchers work with community members to identify problems, with the community setting the agenda and priorities (May, Mendelson, & Ferketich, 1995).

As the *first step* of the development process for this study, members of the research team travelled to the 30

health districts in the province to establish collaborative relationships with the health district boards and to assess perceptions of the need for a study of rural dementia care. The *second step* was to seek input from key stakeholders into the objectives and design of the study. A one-day workshop was attended by 19 directors of care of rural nursing homes and 29 health district board representatives (board members, management staff, community care managers, case managers, and long-term care staff) representing 27 of the 30 health districts in the province.

As a result of the workshop and meetings with the health district boards, the planned study was broadened to include both institutional and community care of persons with dementia. The study was designed to reflect participants' interests and information needs, with the following objectives: (1) to identify and describe challenges and opportunities in caring for rural Saskatchewan residents with dementia (2) to estimate the number of elderly persons with dementia who were nursing home residents or home care clients in rural Saskatchewan, (3) to describe the physical and social environments of rural nursing homes in the province, and (4) to make recommendations for health policy aimed at improving the quality of life of rural residents with dementia and their caregivers. The *third step* was to test the study design package (methods, instruments, procedures) by conducting a comprehensive pilot study. We randomly selected one of the 15 rural districts interested in hosting the pilot study. The communities' responses to the proposed study were very positive. All 30 health district boards endorsed the study.

## Method

### *Study design*

The study design that emerged from the development process reflects the participants' research priorities. The first objective, to identify and describe challenges and opportunities in caring for rural elderly with dementia, was addressed using an *exploratory qualitative design* because of the nature of the question and the limited knowledge base regarding issues associated with rural dementia care. The goal was to explore a broad range of perspectives across the continuum of care, to identify hypotheses for future study, and to provide contextual information that would complement data obtained using other strategies. Methods and selected findings from the exploratory study are reported in this paper. The second and third objectives were addressed with a *descriptive design* that used primarily quantitative measures, including an audit of nursing home charts, structured interviews with nursing directors, a survey questionnaire sent to all care staff in the facilities, and an assessment of

the physical and social environments of the facilities. Methods and findings related to the descriptive design will be reported elsewhere.

### *Setting*

Approximately 30% of the population of Canada and 50% of the population of Saskatchewan lives in rural areas with less than 10,000 persons (Statistics Canada, 1997). Agriculture is the primary industry in the province, which produces 54% of the wheat grown in Canada. The health district in which the pilot study was conducted included large areas of parkland, with mixed cattle and grain farming predominating. The population size of the seven towns in which nursing homes were located ranged from 345 to 1234 persons (median = 435) (Saskatchewan Bureau of Statistics, 1997). With 16,000 km<sup>2</sup> (6178 square miles) and 20,000 people, the district had a population density of 1.3 persons per km<sup>2</sup> or 3.4 persons per square mile (Saskatchewan Health, 1998) and therefore meets the criteria for a "frontier" area, defined as six or fewer persons per square mile (Wagenfield, 2000). Although the overall population of the district has been decreasing over time, the proportion of elderly has been increasing. At the time of the study 15.8% of the population were 65 years of age or older (Saskatchewan Bureau of Statistics, 1997). The district had four hospitals and seven nursing homes (17 to 36 beds), with home care administered through three divisional offices. Services in nursing homes and through home care were heavily subsidized by the health district through government, with fees calculated on a sliding scale based on income up to a monthly maximum. Home care services included nursing, personal care, homemaking, respite, Meals on Wheels, and palliative care. The majority of these services are provided by registered nurses and home health aides. Aides were required to complete a 30-week pre-employment or equivalent "on-the-job" training program. Day care was provided on an ad hoc basis in most of the seven nursing homes.

### *Sample selection and procedure*

To address the first objective, we conducted separate focus groups with seven different stakeholder groups (italicised) representing both formal and informal caregivers in the facilities and community. Where possible, we used random sampling to select focus group participants.

### *Formal caregivers*

Eleven *directors of care* (nursing homes, hospitals, and home care) attended a focus group, along with the district's director of health care services. Letters of invitation were sent to all *nursing home staff* involved in hands-on care, asking them to return a signed consent

form if they were interested in participating in the study. Most of the direct personal care in nursing homes was provided by the resident attendants who must complete a 30-week pre-employment program or an equivalent on-the-job program. After consent forms were received, we used stratified random sampling to select one registered nurse, resident attendant, and activity worker from within each nursing home to attend a focus group. Because there were seven facilities and three staff categories represented from each facility, two meetings were held with nursing home staff to control group size. Stratified random sampling was used to select a registered nurse and home health aide from each of the three *home care* divisions in the district. An assessor-coordinator and scheduler from each division also attended, as well as the district occupational therapist, for a total of 13 participants. Three *health district board members* volunteered to attend a focus group. Input from *physicians* was obtained by meeting with the medical advisory committee, at which seven of the nine district physicians were present.

#### *Family members*

*Family caregivers in the community* were difficult to recruit. When other strategies met with limited success, home care directors volunteered to call clients who were caring for a person with dementia at home, to ask for their consent for us to contact them. Because of the small number of family caregivers identified, random sampling was not feasible. Four of the seven family members who agreed to participate were able to attend on the scheduled day, including 1 daughter and 3 daughters-in-law. *Family members of residents in rural nursing homes* were recruited by asking the facility directors to list all residents with a documented dementia diagnosis and a family member who had regular contact with their institutionalized relative, to whom information and consent forms were mailed. Of the eleven consents returned, nine family members were able to attend the focus group and describe their experiences before and after placing their relative in the home. The group included 3 spouses (one husband and two wives), 5 daughters, and 1 niece. Among the family members participating in the study, only one participant was male.

#### *Data collection and analysis*

Focus groups are a qualitative research technique for learning about participants' experiences and perspectives, with the goal of identifying trends and patterns in perceptions (Krueger, 1994). We used a semi-structured interview guide to focus the discussion on issues related to the care of persons with dementia in rural areas and to explore the perceived challenges and opportunities of rural dementia care. Open-ended questions established a

general direction for the interview while offering opportunities for participants to direct the conversation to areas of concern to them. The focus groups were conducted before the descriptive survey questionnaire was mailed to staff, to avoid bias from exposure to survey questions. The interviews were held in two towns using meeting rooms in the local hospitals. Family members were given an honorarium to cover travel expenses and lunch was provided. Home care and long-term care staff attended during work hours and were replaced for half a day to ensure that staffing levels would not be affected by the study. All interviews were conducted by the principal investigator (DM), tape-recorded and transcribed verbatim, then checked for accuracy. The interviews lasted 1.5–2 h. Ethical approval was obtained from the University of Saskatchewan ethics committee. Signed consents were obtained from all participants.

Thematic analysis (Strauss & Corbin, 1998) was conducted using the constant comparative method described by Glaser and Strauss (1967), in which the researcher searches for similarities and differences among the data. Transcripts were reviewed and codes developed to reflect the meaning in the data. As the analysis progressed these codes were collapsed into a smaller number of categories that became the major themes of the study. Memos were used to record and develop ideas about emerging themes.

## **Results**

The goal of each focus group interview was to allow issues of concern to group members to emerge, and not to obtain reactions to themes identified in other groups. Although the guide did not include direct questions about use of community-based supportive services, the theme of resistance to or non-use of formal services by family caregivers of persons with dementia ran throughout the interviews with home care staff and directors. Family members focussed on different issues, such as problems in getting their relatives' condition recognized by health care professionals and other family members; challenges in obtaining a nursing home bed; and the constant worry, uncertainty, and stress. Family members seldom spoke directly about gaps or problems with existing services, although implications for service delivery were implicit in their concerns. Many of the families' concerns centred on the stress they experienced while waiting for permanent placement of their relative in a nursing home, when they had reached the threshold where they perceived continued caregiving to be impossible, even with the implementation of community-based services. Data from both families and home care staff showed that family caregivers wanted to keep their relative at home as long as possible, often at great

physical and emotional cost, but they eventually reached a crisis point where continued care in the community was no longer feasible and the need for placement became urgent. In addition to barriers to utilization of formal services by families caring for a relative with dementia at home, home care staff also described the consequences of low service use and strategies for encouraging greater use of services. These health care providers had considerable experience in working with caregivers and individuals with dementia, which they stated made up the majority of their clientele. Perhaps because of this experience they were able to see patterns related to non-use of services that were not evident to individual family caregivers who were immersed in day-to-day caregiving responsibilities and who had only their own personal experience to draw on. The quotations used to illustrate the results are primarily from home care staff, although family members did describe several barriers related to service acceptability and acceptability.

#### *Factors influencing family caregivers' use of community-based services*

Analysis of the focus group data revealed eight categories of barriers to use of services: the stigma of dementia, lack of privacy, beliefs and attitudes, lack of awareness, financial barriers, acceptability of services, and challenges in service delivery.

#### *Stigma of dementia*

The stigma associated with dementia was a consistent theme throughout the study and had a direct and indirect impact on caregivers' use of services through its effect on caregivers themselves, other family members, and the community. Many participants stated that dementia is different from other types of illness because it is associated with mental illness, which has a long history of misunderstanding, fear, and stigma. They suggested that better public awareness about dementia would help to change attitudes about the disease and make it possible for people to talk about and acknowledge it in their family members and others in the community. If caregivers were more comfortable discussing the difficulties they experienced, others might recognize the strain they are under and be able to offer support, and caregivers could openly seek out information about dementia and resources available in the community. Several participants suggested that attitudes may be beginning to change as a result of increasing awareness.

I think it's the era, too, it's associated with mental illness, and...most of the generation that it's hitting, you know, didn't talk about mental illness. You were locked up and you were crazy, that was it. You didn't

mention any of that. Everything was hush-hush, and it was to be ashamed of. And maybe when our generation gets there it will be better, because people will admit "Well, ya, I have early Alzheimer's" (home care staff).

Like it's still very much a stigma...someone can have a heart attack and everyone is desperately concerned. Someone is obviously slipping into dementia and people will just race as far away from them as they can get, as if they've got some dreaded communicable disease. And yet, if you've got a stroke or heart attack victim, people will come to visit you (family caregiver).

Home care staff suggested that the stigma is linked to the socially inappropriate behaviors common to dementia. Many people are uncomfortable and embarrassed by these behaviors and avoid contact with individuals with dementia. Family members want to "hold the image" that community members have of their relative, so they isolate themselves from others, including health care providers such as home care staff, who often know the family.

It's like a social embarrassment. You know, "my husband's wetting his pants, well, I can't let anybody know that. So he's fine, you know." And then they [caregivers] isolate themselves...to keep it in their homes, so nobody knows (home care staff).

But I think when you talk about the stigma... I mean there's lots of things in caring for a demented person that are, you know, really personal things. Like you're often dealing with sexual inappropriateness, you're dealing with incontinence... But in my mother's generation...that was something you never talked about. And to admit that those things are there...that's how some of the stigma comes (home care staff).

Home care staff felt that one of the biggest issues affecting attendance at support groups was the stigma of dementia, and the desire to protect the privacy of the person with dementia and the family. The Alzheimer support group in the district no longer met because too few people were attending. Staff speculated that family members might attend a group outside of their community, where they were not known, but increased travel time and cost becomes a barrier.

I think that is the same as maybe an alcohol support group. You know, you'd shy away from it, and say that, "Well, you know, if I go to that, then people will know that so-and-so has Alzheimer's or whatever" (home care staff).

Families resist them [support groups]. They absolutely resist them. They don't want to be seen there,

or something, I don't know what it is. They have a hard time getting away. And they won't take the help coming in, so that they CAN get away (home care staff).

I think another reason is, is because it is small communities, and they just don't want to be talking to their neighbors about it, you know. Like, it would probably be better if the person from [Town A] went to [Town B] or [Town C] to a support group, than to [Town A]. You know? Some place where they didn't know anybody (home care staff).

The stigma associated with dementia was linked to denial in primary caregivers and other family members. In situations where the primary caregiver accepted the dementia diagnosis, but other family members did not, the misunderstanding and conflict within the family was painful for the caregiver and resulted in lack of support from other family members. The quotations below illustrate how denial by other family members also made it more difficult for the caregiver to seek out support or services.

That's the biggest one, denial. And they refuse help in the home, the caregivers, a lot of times...a lot of them don't want to admit to the community that their husband, wife, whatever, has a problem. So they don't tell [home care staff] a lot of information as well (home care staff).

Maybe the caregiver isn't in denial, but maybe the family is. And if the family's in denial, it's awful hard for you to go [to a support group], if they think that Dad doesn't have it.... If your kids come home for an hour today, they're fine! Everything you talk about, they seem to answer right.... So I think that could probably be a part of it, that people wouldn't go. I mean, if your family is dead against it, and say that, "Well, why would you go to that? Dad doesn't have that." Well, it would be pretty tough (home care staff).

People in the community were described as "protecting" the person with dementia and their caregiver by denying anything was wrong. The community and the caregiver "pretended" that there was nothing wrong, "covering up" for inappropriate behavior or when the demented relative got lost in town. This resulted in a loss of support to the caregiver because the caregiver could not ask for help and people in the community could not offer it. The stigma of dementia was seen as underlying this phenomenon, which participants felt did not happen in the case of physical illnesses. The analogy to alcoholism was made by a number of participants.

They [community] also do a support that perhaps is a bit like the [spouse] with the alcoholic who phones the boss and says, "well, he's sick, he's got the flu", and not "he's drunk out of his mind". The community pretends along with the family that there's nothing wrong, you know? They don't say to her, "Boy, your husband's getting worse." Everybody's pretending that this isn't existing. "I just brought him home, he was a little bit lost today, you know, maybe he's not feeling so good" (home care staff).

Participants suggested that people in close-knit rural communities are more likely to have this "protective instinct", but that these kinds of actions are not supportive for families caring for a relative with dementia and it may prevent them from seeking help and using community resources. As one home care staff member stated "It's kind of backwards. It doesn't make any sense, but it's what happens."

I just notice that it's a lot closer knit in the smaller communities...it's like a protective thing, you know, they're protecting those that are in the community, and that's probably where a lot of the denial [comes from], and "Let's look after this"... That support is wonderful, as long as there's the ability to move out, and then to go for help when you need it, outside of that (home care staff).

It's kindness in a way, out in a small community, but it's still enabling this situation to go on, and caregiver's not going to get any help (home care staff).

#### *Lack of privacy*

Lack of privacy and anonymity, which were often linked to the issue of stigma, also contributed to families' resistance to using support services. Living in a rural area, where one's activities were likely to be observed and discussed, was seen to make it more difficult to maintain privacy. Although the closeness of rural communities was identified as a strength, in that neighbors would "watch out" for the person with dementia, anonymity was impossible.

The rural area would be more of a fishbowl existence, as opposed to the cities, because everything as a family you do, it's very much scrutinized by coffee row (home care staff).

[In the city] it wouldn't be everybody you know would know that something's wrong with your husband. Everywhere...you can go into the store, they know you. If you go to the hairdresser's, they know you. You go to the dentist, they know you. Or

to the hospital, you go to the doctor, you go to the bank. Everybody knows (home care staff).

Home care staff stated that because they were part of the same small community, families were concerned about staff maintaining confidentiality outside their home. Because of the nature of behaviors that can occur with dementia, some families would rather have someone they do not know, and who is not part of the community, caring for their relative.

But then the next time she [family caregiver] sees you [home care staff], you're in church, and you're preparing at the community supper or something like that, and they want to know for sure that you're not going to be gossiping about what's going on. Because...gossip is a **BIG** thing in rural communities. People talk about their neighbors all the time (home care staff).

[In a city] you wouldn't have one of your relatives come around to look after you, you know? It wouldn't be your niece or your granddaughter coming in to look after you, it would be somebody strange, which is probably more acceptable (home care staff).

#### *Beliefs and attitudes*

Accepting services such as home care was seen as a public admission by the caregiver that not only did their family member have dementia, but that the caregiver was unable to manage without help. The self-reliance and independence of the current generation of elderly were seen as additional factors that discouraged use of community-based services. Some caregivers were afraid of being a burden on the "system" and felt that by accepting services they might be taking help away from someone who needed it more.

But we're dealing with a lot of older people, and they've always been very independent. That's the way they've lived their lives, and they don't want anyone intruding in their lives (home care staff).

With some of the older people who have Alzheimer's, they lived in a different time from us, and I think they had a different idea about what you're supposed to be able to handle, and what kind of stresses you should be able to cope with (home care staff).

Caregivers felt that they needed a legitimate reason for using respite services. Using the time to do something for themselves might be perceived as "frivolous". Home care staff also observed that even though the caregivers paid for the service, they sometimes saw the workers' assistance as a favor and they did

not want to be seen as accepting charity. Families sought reassurance that they were not alone in using services and that others also needed help.

It's got to be a respectable reason why you have to leave. "I've got to go to a wedding." So that's okay. But not, "I'm going to the city to get my hair done." That's frivolous, and you shouldn't be doing it...you've got to have a very good reason (home care staff).

It's almost like they [family caregivers] don't see it as a job. They don't see home care and the home health aides as workers—they see it like these friendly people coming into their home to help them (home care staff).

The association of home care and respite services with dependence and decline were suggested as additional factors influencing caregivers' decisions regarding service use. Home care was seen as "the step before the nursing home". The location of respite beds in nursing homes was a possible deterrent, because admission to nursing homes was viewed as permanent. Respite beds located in acute care facilities were seen as more acceptable by some people.

I've seen some people who go into respite [in a nursing home] and they're really afraid then that they'll end up going into the nursing home part. Some people want nothing at all to do with that nursing home part...they know when they're going in there, that they're not coming out (home care staff).

When they moved the respite bed to the nursing home, people were not happy, because it was OK to be in the hospital. "Walter's in the hospital and the doctor said he had to be admitted." That was OK. But "Walter's in the nursing home"—different game (home care staff).

Guilt was identified as another factor that influenced caregivers' use of services. Home care staff stated that many family members saw caregiving as their responsibility and they felt very guilty about accepting home care services. The decision to place their relative in a nursing home caused extreme feelings of guilt. Most caregivers needed a great deal of encouragement and support from other family members and health care providers to accept help with care at home, or to make the decision to relinquish care. This was especially true for elderly women who felt that they had failed because they could no longer look after their husband.

Years ago, too, the people that we are looking after now, they looked after their grandparents, and their Mom and Dad, or whatever, so when they have to

put [their spouse] in a nursing home, they're going, "Well, I should be able to do this" (home care staff).

They [caregiver] need to be reminded, or told that they are doing a good job. And "Yes, you've taken care of him long enough. It's all right to let go of it." And some of them just feel so guilty for using outside help. So there's a lot of that (home care staff).

#### *Lack of awareness*

Health care providers felt that families needed to use supportive services earlier, rather than waiting until a crisis situation occurred or the caregiver became exhausted. They felt that lack of information about the availability of services and the importance of using them to prevent burnout was a factor. Home care staff observed that many caregivers did not understand that respite and other services were there to help people like them. They needed to be clearly informed about how the service could benefit them specifically.

But if they knew that this was okay [to take some time for themselves], you know, we have respite, and it's for this purpose. If they could know more, that it was an okay thing to do, then they would maybe take it more (home care staff).

In the year prior to data collection for this study, changes were made in the delivery of home care services in this district and many others throughout the province. In an effort to maximize the available resources and personnel in the face of funding cutbacks from government, the district restricted homemaking services to clients who also needed personal care. Another change was the increased education level of the home health aides, from little or no formal training to the requirement for a Special Care Aide diploma. The aides felt that many people viewed them as untrained homemakers who provided a "glorified maid service", and therefore did not take advantage of the aide's knowledge and expertise.

We need to be able to identify the home health aides as being "trained people". I always emphasize that these are not just people off the street, these are people with training, and knowledge, they've done it before, and they know how. And usually once they get in and show their professionalism, then everything relaxes (home care staff).

But the people [family caregivers] who are dealing with dementia clients, for example, who really need a home health aide in there who can give them some assistance with this person, they're still thinking of the home health aides as [housekeepers].

"Oh, well, I don't need anybody to clean because my family is doing the cleaning for me" (home care staff).

Lack of understanding about the impact of dementia on the affected person was identified as another factor that affected service use. Family members, friends, and others in the community may not understand how dementia leads to loss of ability to communicate verbally, so that the caregiver needs to have other opportunities for social interaction and contact. Because of this, caregivers may not receive encouragement to use respite so that they can participate in social activities. Attitudes and beliefs about what is acceptable social behavior for women also may result in lack of support for caregivers to use respite to meet their own needs.

I think too, that maybe respite in rural areas, we don't acknowledge the strain, the social strain on people, you know? People understand what the physical work is, but people are not really always ready to acknowledge the fact that somebody's trapped in a place with only one adult, and there's no conversation. Because you can't carry on a conversation [with person with dementia], you can't have any feedback, and I think a little bit in rural areas, especially if the wife decides to go out and visit, you know, that's not always looked on very favorably—to be socializing away from home (home care staff).

#### *Acceptability and accessibility of services*

Although home care staff were more likely to describe barriers to service use, family caregivers identified several factors related to acceptability and accessibility of services. Several families described the difficulties they experienced in having their observations of cognitive decline in their relative recognized and validated by a health professional. Access to experts in assessment and management of Alzheimer disease and related dementias who could diagnose the problem was important, because a diagnosis was a prerequisite for learning about and accessing community resources. Several family members felt that this access was limited in rural areas.

I would say that our problem was mostly the fact that you knew the person was not well, was having a lot of problems, but when you take them to the doctor, the doctor would say, "Oh, they're just getting old—everybody gets forgetful." And you would have no help from that (family caregiver).

Distance to services was another barrier identified by families and staff. In rural areas, travel is involved for those providing and those using services. The additional time required to travel to a support



group, for example, meant greater respite costs. Day care was offered in many of the nursing homes, but for those on farms, transportation to the program was a problem. In the second quotation below, an elderly woman describes how the challenges of getting her husband out of the car after bringing him home from day care in town outweighed the program's benefits.

Distance to travel—I'm sure that's a factor [in use of support groups]. You know, you can't just get somebody to come and sit with your husband for an hour and a half...it's not like going in the city where you go three blocks and then you're back...here you've got to get somebody to look after him for two, two and half hours, maybe more...so it adds up to money, if you've got to pay someone like that (family caregiver).

In the first place it was difficult to get my husband into the car, but when I went to get him after 6 hours, and he'd be kind of tired out because he was all day in this strange place, well I might be able to get him into the car, but when I got him home, it would take several hours of persuasion [to get him out]...that's practically impossible, so it wasn't worth it. You know it's different in cities, they have these special buses...but in rural areas, it's more of a chore to do that (family caregiver).

The limits on the amount and types of service that could be obtained in a given time period also were issues for family caregivers, who sometimes were left trying to patch together help from home care, friends, and family in order to get away for a day or two. The eligibility rules for homemaking services also were a concern for caregivers whose relative needed help only with cleaning or meal preparation and who could not obtain these services from home care.

The area that home care falls down in, to me, is the worker could only come in for so many hours...say I was going to get away for a day, I couldn't get the home care to fill in for that 24h. I'd have to make some other arrangements in between (family caregiver).

You don't get as much home care, as far as somebody coming in to help you wash walls or windows or help make breakfast, dinner, and supper...yes, they'll do the nursing care, but the home care that was initially set up to help people actually stay IN the home, they're really cutting back on a lot of that (family caregiver).

There were also changes in how home care services were organized and delivered, with management centralized in a few locations rather than in each

small community. Home care managers who lived in the same community as the clients were more likely to know how families were coping and what their needs were, and were more proactive in relationships with caregivers.

The director of care of the nursing home, the home care nurse, and the director of care of home care phoned every member of the family and said "listen, you come to a meeting, [the main caregivers] are at the breaking point, they cannot handle this any longer". But I don't think that would happen now because I don't think we have that personal contact...they don't know us. Like we were in the community, thankfully people could see the struggle, could understand (family caregiver).

Home care staff stressed the need to provide more support for family caregivers, but some families felt that home care assessors underestimated their needs. Several caregivers criticized the practice of conducting assessments using the person with dementia as the only informant, as often the individual denied having problems. Families wondered if there was a financial motivation for underestimating need, because of the cost savings to the district.

Although home care services were subsidized by the health district, the cost of services was described as a deterrent to use of home care services for some families. Home care staff felt that, in some cases, the actual cost was a financial hardship and in other cases, the barrier was more related to beliefs and attitudes. The current cohort of seniors was described as being reluctant to pay for relief time for themselves, after a lifetime of hard work and frugality.

We have a large number of elderly people in our district, and there are lots of them that will NOT PAY for home care, no matter what. They worked hard all their lives for that money and they're NOT giving it to anybody (home care staff).

They're really worried because their medications are costing more. Everything is costing more. Then we're coming in and saying, "Yes, you need that service...you need Meals on Wheels, you need respite." They worry about it (home care staff).

#### *Service delivery challenges*

In some cases primary caregivers wanted formal services but refused help because other family members denied that their relative had a problem that required this help. Often the person with dementia lived alone and would not let service providers into the home. When the demented person refused assessment of their health or mental competence, family members stood by help-

lessly, while remaining very concerned about their relative's safety.

We had home care [for mother] until they [home care staff] got accused of stealing, got fired, got thrown out, got the door locked on them. That was in about a 2-week period. So home care then phoned the nursing home, phoned us, and said "We cannot handle it" (family caregiver).

She [mother] is either going to burn the place down or she's going to be crippled for life. Then maybe somebody will listen, you know, that something needs to be done (family caregiver).

The behaviors associated with dementing illnesses make service provision challenging. Problems such as agitation or disturbed sleep are often unpredictable and vary from day to day, which makes it difficult to have the service in place when it is needed most. For example, while home care can provide night respite for two consecutive nights so that the caregiver can sleep, it may happen that the person with dementia sleeps well on those two nights and is up all of the next night. Staff stated that providing support to people with dementia and their caregivers is more difficult than in cases of physical disability, because the need is so great and extends around the clock. A certain level of service is needed to make a difference in outcomes such as caregiver stress. Despite the challenges of providing support for family caregivers, a deep concern for the welfare of the person with dementia and the caregiver was plainly evident in interviews with home care staff. Their perseverance in establishing and maintaining contact with families is evident in the following quotations.

We've had a couple of people living alone...we couldn't get hardly past the front door, but we didn't quit. As long as she would let us in the front door, we kept sending nurses and home health aides...and it takes MONTHS before they start developing trust, and then you can start helping them more. This was two years of trying (home care staff).

It's just nursing going in there to try encourage, support. But the lady injured herself very badly...and she was hospitalized of course, so that was our foot in the door. And it's going to remain. Like they check her [injury] and everything, it's all healed over, but that's still their excuse for going in...the true reason is to give him [caregiver] emotional support and encouragement [and] monitor the situation. Because they see his health slipping, and then we have the concern if something happens to HIM. What happens then? (home care staff).

### *Consequences of not using support services*

Home care staff observed that in many cases caregivers refused to accept any help until they had reached a crisis situation, which often involved a breakdown in the caregiver's health. Home care staff tried to monitor the caregiver's stress and to encourage them to use services such as respite, but they were able to do this only if they were already in the home providing a service. In many instances they were aware that a caregiver was becoming stressed, but they were unable to provide support. Staff clearly saw caregiving for a relative with dementia as a tremendously demanding job with a high risk for exhaustion and they felt that not enough was being done to provide relief for family caregivers. One home care staff member stated that, in most cases, the needs of the person with dementia were being met, but the needs of the caregiver were not.

We have to do something for these people or else ALL these people are going to end up in nursing homes, and not only is the person with dementia going to be there, but the person that's looking after them is going to be somewhere too, because they're exhausted...you can't work 24 h a day (home care staff).

And often it's the caregiver that ends up sick, that ends up in a crisis, and that's when for SURE we have to do something. But it shouldn't get to that level, but it often does. That's the only way that they'll give up, is that they physically burn out. Physically crash and burn (home care staff).

In these crisis situations it was difficult for home care to provide the level of service needed and placement of the person with dementia in a long-term care facility was often the only option. Even in situations where they were providing some service, home care staff often felt it was not enough, but they could not convince the caregiver to accept more help.

We [home care] are seeing them when they're—they come when they ARE a problem. And at that point it's usually too late for that caregiver to just even get enough rest (home care staff).

And those that have a caregiver in the house, we find it's very difficult sometimes to GIVE them help with home care, because they will NOT accept it. The caregivers are burned out. You can see it, but they will not take help. They want to shoulder the burden, they don't want the community to know their secret...you just have to keep repeating your offer of respite care, and eventually they may start using it. But a lot of times they just won't (home care staff).

Availability of a long-term care bed was often a problem in situations where the caregiver suddenly became unable to keep their relative at home as a result of a crisis in their own health. The care recipient was often placed in a temporary respite bed in a hospital or nursing home while waiting for a permanent bed. Respite admissions were restricted to one month, and although there was some flexibility if the demand for respite was low, this was not usually the case. Waiting for a permanent bed was very stressful because families had to be prepared to take their relative home at the end of the month, unless another respite admission could be arranged elsewhere. One family member described the “hopeless, helpless feeling” of not knowing whether a bed would be found and how they would manage if they had to take their relative home again. In some cases individuals were transferred to several different nursing homes in the district before placement could be arranged, a situation that was very disruptive for the person with dementia and their family. Once temporary respite had been found, some family members refused to take their relative home at the end of the period, because they just could not manage.

It’s going to be very hard on her, because she’s going in there [respite] now, and she’s going to go to another one, and then she’s booked in there for July, then she’s out for August, and she’s booked for September-October. She’s going to be like a yo-yo (family caregiver).

They were hollering and hollering [to take family member home at end of respite period], we were just frantic to try and get a place. We COULDN’T keep him at home. In fact, I told the doctor, “I refuse to take him home.” I didn’t know what else to do. But anyhow, it worked out. He passed away within two weeks (family caregiver).

#### *Strategies for increasing service utilization*

Ideas for increasing use of community-based services by family caregivers emerged in the interviews with home care staff. Staff suggested that if the caregiver has regular contact with the health care system, it might help to prevent the crises that occur when the home situation breaks down and immediate placement of the person with dementia is necessary. For example, when home care is involved with a family caring for someone with dementia, they can monitor the situation and provide the continued offers of support that are often necessary to help caregivers make the decision to use the available services. If it becomes necessary, plans could be made for placement well in advance, avoiding the stress on the family and the health care system that are associated

with finding a nursing home bed after a crisis has occurred.

Home care staff felt that lack of understanding about the purpose of available resources was a barrier to their use, because many caregivers did not see how a particular service would be useful to them. Caregivers needed to be informed about what was available, but they also needed help in making a connection to their own circumstances, along with reassurance that they were not misusing the system. Study participants also identified a need for improved public education about dementia to begin breaking down the fear and misunderstanding surrounding dementia. One way to do this would be to increase the amount of contact between people in the community and nursing home residents with dementia, by taking residents to local restaurants for coffee or by holding community events in the nursing home. Media such as television and radio could be used to improve public awareness and reduce stigma.

Oh it [stigma] is still there. So I think even educating right from the early, early grades, that this is a disease, this is why your grandpa is like this, or this is why your grandma’s like this. If you really want to go preventive, way, way back (home care staff).

It’s public awareness, you know...how they’re stressing you to have Home Care—they have to get more knowledge out, even to our kids. Because the man walking down the street isn’t crazy, there’s something wrong with him. And like maybe he needs help. We need to get more awareness to the public (home care staff).

Because of the change in emphasis in the home care program, from supportive homemaking services to more “professional” services, some of the staff felt that it might take time for perceptions about the role of home care staff, especially the home health aides, to change. One person suggested that as people see home care services working for other families, they might think about using them too. Another suggestion for providing support and increasing family awareness of available resources and the potential benefits were using a “buddy system” to link former caregivers to family members who were newer to the caregiving role.

#### **Discussion**

Results of focus groups with family caregivers and home care staff showed that caregivers supporting a relative with dementia at home experienced tremendous stress, yet home care staff clearly perceived that caregivers were reluctant to use services that might help to relieve their stress. It was unlikely that staff’s desire to alleviate caregiver burden by increasing service use was

motivated by personal or financial gain, because these were non-profit services and the home care system was already facing funding and staffing shortages. From the staff's perspective, requests for help were often not made until a crisis situation that made continued caregiving at home difficult or impossible, even with the implementation of services in the home. Home care staff identified a number of factors that they felt were contributing to "resistance" to service use. This term implies that families were aware of available resources but declined to use them, but it is unclear whether families considered but consciously rejected help from existing services, were unaware of existing services, or simply did not think of seeking out help.

As suggested in the introduction to this paper, the finding that home care staff were more likely than family members to report barriers to service use may be related to the broader scope of experience of home care staff in working with many caregivers compared to the intense but singular experience of individual family members. More research is needed to determine the extent to which the barriers identified by staff are in fact hindering the use of services by family members. It is possible that existing services are not meeting the needs of these rural caregivers. Several family members noted the restrictions in hours of service that could be received from home care and the limited availability of homemaking services. The same factors that were identified by staff as inhibiting service use (e.g., self-reliance, desire to protect their relative's dignity) may also inhibit family members from talking about their needs and fully recognizing the difficulty of their caregiver role. In a study of Scottish caregivers, Milligan (2000, p. 52) reported that "Many carers do not recognize the 'provider' role that they play within the caring network, preferring rather to rationalize their contribution to care as simply 'looking after mum or dad' (or another close relative)". Milligan also found that the sense of duty, love, and guilt experienced by caregivers constrained their ability to maximize supportive resources.

The issue of stigma was a pervasive theme. As described in the literature (Kenny, 2001), the concept of stigma involves attitudes, feelings, and behaviors, and implies a negative label being placed on an individual or group that manifests itself in prejudice, discrimination, fear, distrust, and stereotyping. As in the present study, Connell et al. (1996), who used focus groups with family and professional caregivers of persons with dementia in a rural area, found that the commonly held myths and misconceptions about dementia influenced how the family and community responded to people with dementia. Both improved public awareness and earlier, continuous contact with family members by knowledgeable health care professionals are needed to change responses to dementia. Study findings suggest that a case management approach that begins early in the caregiv-

ing trajectory might increase the likelihood that caregivers know about and are encouraged to use available services. The case manager could act as advocate, provide on-going guidance and support, and enhance continuity of care from the community to the nursing home. Although more research on care transitions and coordination of care in rural areas are needed (Magilvy, 1996), Krout (1997) argued that case management for the rural elderly can prevent hospital and nursing home stays, increase awareness of and access to in-home services, improve service coordination, provide support for family members, and improve quality of life.

Timely intervention depends on early assessment and diagnosis, but families in this study felt that health care professionals lacked adequate skills in early assessment and diagnosis and often were not aware of available services in their own community. Early diagnosis would alleviate stress resulting from uncertainty about what was happening and allow caregivers to access resources sooner. Several studies have found that physicians need more basic and continuing education regarding dementia (Brown, Mutran, Sloane, & Long, 1998; Cheok, Cohen, & Zuccherro, 1997; Tinsley, Shadid, Li, Offord, & Agerter, 1998). Although difficult to provide in rural areas, continuing education for all health professionals is important, as families rely on them for information.

The issues of independence and privacy, identified in the present study, have been observed in earlier research. Magilvy (1996) points out that concerns about privacy would suggest a preference for formal services, but as participants in the present study indicated, formal caregivers usually live in the same rural community and are well known to potential clients. This fact, combined with the socially unacceptable and embarrassing behaviors common to dementia, were described as deterrents to use of services. Ensuring confidentiality of client information by home care staff is critical to developing and maintaining the trust that is the basis of the caregiver-client relationship. Telephone support strategies have been identified as helpful in facilitating privacy and reducing the need for travel in rural areas (Skipwith, 1994). These benefits would also apply to the video telephony system described by Hanson, Tetley and Clarke (1999), which was developed to provide support and education about respite and long-term care planning to families in their own homes.

The predominance of female caregivers in this study reflects the reality that it is female family members who have traditionally taken on the majority of responsibility for family caregiving, and continue to do so despite their increasing participation in the workforce (Joseph & Hallman, 1998). Many of the daughters and daughters-in-law in this study described feeling overwhelmed by the demands of off-farm employment, helping with farm work, child-rearing, and providing support to their

elderly parents. Gender issues also emerged with respect to elderly women caring for their husbands, with rural cultural values about acceptable behavior for women contributing to social isolation and guilt about accepting help with caregiving.

One of the limitations of this study was the small number of family members actively caring for a relative with dementia at home who were able or willing to participate in the study, because of caregiving responsibilities or reluctance to identify themselves. Some of the participating family members had recently placed their relative in a nursing home and although they were able to look back on their experiences before placement, future research should focus on family members who are currently providing this care. Longitudinal studies are needed to understand the decision-making process that rural family caregivers use in determining if and when they will use formal community-based services, and to explain the differences in the perspectives of family caregivers and home care staff. To what extent are currently available services meeting the needs of rural caregivers? Are problems with awareness, acceptability, accessibility, and adequacy resulting in low use of services? What needs do family members identify, and what role do they see for formal services in assisting them? Answers to these questions will help in planning effective policies and programs for rural elderly with dementia and their caregivers.

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### References

- Abraham, I., Buckwalter, K., Neese, J., & Fox, J. (1994). Mental health of rural elderly: A research agenda for nursing. *Issues in Mental Health Nursing, 15*, 203–213.
- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) (DSM-IV). Washington, DC: Author.
- Brown, C., Mutran, E., Sloane, P., & Long, K. (1998). Primary care physicians' knowledge and behavior related to Alzheimer Disease. *Journal of Applied Gerontology, 17*, 462–479.
- Bushy, A. (1994). When your client lives in a rural area Part 1: Rural health care delivery issues. *Issues in Mental Health Nursing, 15*, 253–266.
- Canada Mortgage & Housing Corporation (1991). *Maintaining seniors' independence in rural areas: A guide to planning for housing and support services*. Ottawa, ON, Canada: Author.
- Canadian Study of Health and Aging (CSHA) Working Group (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*, 899–913.
- Cheok, A., Cohen, C., & Zuccherro, C. (1997). Diagnosing and managing dementia patients: Practice patterns of family physicians. *Canadian Family Physician, 43*, 477–482.
- Collins, C., Stommel, M., King, S., & Given, C. (1991). Assessment of the attitudes of family caregivers toward community services. *The Gerontologist, 31*(6), 756–761.
- Connell, C., Kole, S., Avey, H., Benedict, C., & Gilman, S. (1996). Attitudes about Alzheimer's disease and the dementia service delivery network among family caregivers and service providers in rural Michigan. *American Journal of Alzheimer's Disease, 11*(3), 15–25.
- Coward, R., Cutler, S., & Mullens, R. (1990). Residential differences in the composition of helping networks of impaired elders. *Family Relations, 39*, 44–50.
- Coward, R., Netzer, J., & Peek, C. (1996). Obstacles to providing high-quality long-term care services for rural elders. In D. Rowles, J. Beaulieu, & W. Myers (Eds.), *Long-term care for the rural elderly: New directions in services, research, and policy* (pp. 10–34). New York: Springer Publishing.
- Coyne, A. (1991). Information and referral service usage among caregiver for dementia patients. *The Gerontologist, 31*(3), 384–388.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine.
- Gräsel, E. (1997). Temporary institutional respite in dementia cases: Who utilizes this form of respite care and what effect does it have? *International Psychogeriatrics, 9*(4), 437–448.
- Green, L., George, M., Daniel, M., Frankish, C., Herbert, C., Bowie, W., & O'Neill, M. (1995). Study of participatory research in health promotion: *Review and recommendations for the development of participatory research in health promotion in Canada*. Institute of Health Promotion Research, University of British Columbia, BC, Canada.
- Hanson, E., Tetley, J., & Clarke, A. (1999). A multimedia intervention to support family caregivers. *The Gerontologist, 39*(6), 736–741.
- Joseph, A., & Hallman, B. (1998). Over the hill and far away: Distance as a barrier to the provision of assistance to elderly relatives. *Social Science & Medicine, 46*(6), 631–639.
- Keefover, R., Rankin, E., Keyl, P., Wells, J., Martin, J., & Shaw, J. (1996). Dementing illnesses in rural populations: The need for research and challenges confronting investigators. *The Journal of Rural Health, 12*, 178–187.
- Kenny, J. (2001). Cloaked in secrecy and shame. *Canadian Nurse, 97*(1), 20–24.
- Krout, J. (1994). An overview of older rural populations and community-based services. In J. Krout (Ed.), *Providing community-based services to the rural elderly* (pp. 3–18). Thousand Oaks, CA: Sage.
- Krout, J. (1997). Barriers to providing case management to rural older persons. *Journal of Case Management, 6*(4), 142–150.
- Krueger, R. (1994). *Focus groups: a practical guide for applied research*. Thousand Oaks, CA: Sage.

- Long, K., & Weinert, C. (1989). Rural nursing: Developing the theory base. *Scholarly Inquiry in Nursing Practice*, 3, 113–127.
- Magilvy, J. (1996). The role of rural home- and community-based services. In G. Rowles, J. Beaulieu, & W. Myers (Eds.), *Long-term care for the rural elderly* (pp. 64–84). New York: Springer.
- May, K., Mendelson, C., & Ferketich, S. (1995). Community empowerment in rural health care. *Public Health Nursing*, 12(1), 25–30.
- McCabe, B., Sand, B., Yeaworth, R., & Nieveen, J. (1995). Availability and utilization of services by Alzheimer's Disease caregivers. *Journal of Gerontological Nursing*, 21, 14–22.
- Milligan, C. (2000). "Bearing the burden": Towards a restructured geography of caring. *Area*, 32(1), 49–58.
- Rudin, D. (1994). Caregiver attitudes regarding utilization and usefulness of respite services for people with Alzheimer's disease. *Journal of Gerontological Social Work*, 23(1&2), 85–107.
- Saskatchewan Bureau of Statistics (1997). *Saskatchewan 1991–1996 census population*. Regina, SK, Canada: Author.
- Saskatchewan Health (1998). *Community Profile System*. Regina, SK: Saskatchewan Health, Corporate Information and Technology Branch.
- Schoenberg, N., & Coward, R. (1998). Residential differences in attitudes about barriers to using community-based services among older adults. *Journal of Rural Health*, 14(4), 295–304.
- Shope, J., Holmes, S., Sharpe, P., Goodman, C., Izenson, S., Gilman, S., & Foster, N. (1993). Services for persons with dementia and their families: A survey of information and referral agencies in Michigan. *The Gerontologist*, 33, 529–533.
- Skipwith, D. (1994). Telephone counselling interventions with caregivers of elders. *Journal of Psychosocial Nursing*, 32, 7–12.
- Statistics Canada (1997). *Census 1996: Population and dwelling counts* (No. 93-357-XPB). Ministry of Industry, Ottawa, ON, Canada.
- Stoller, E. (1996). The role of the family in rural long-term care. In G. Rowles, J. Beaulieu, & W. Myers (Eds.), *Long-term care for the rural elderly* (pp. 35–63). New York: Springer.
- Stoller, E., & Pugliesi, K. (1988). Informal networks of community based elderly: Changes in composition over time. *Research on Aging*, 10, 499–516.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research Techniques and procedures for developing grounded theory*. (2nd ed.). London: Sage Publications.
- Tinsley, J., Shadid, G., Li, H., Offord, K., & Agerter, D. (1998). A survey of family physicians and psychiatrists: Psychotropic prescribing practices and educational needs. *General Hospital Psychiatry*, 20, 360–367.
- Vale, M. (2000). What is Alzheimer's disease and who will be affected? *Geriatrics and Aging*, 3(7), 25.
- Wagenfield, M. (2000). Delivering mental health services to the persistently and seriously mental ill in frontier areas. *Journal of Rural Health*, 16(1), 91–96.
- Weinert, C., & Long, K. (1987). Understanding the health care needs of rural families. *Journal of Family Relations*, 36, 450–455.