

## ORIGINAL RESEARCH

# Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada

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## ABSTRACT

**Introduction:** Rural and remote settings pose particular healthcare and service delivery challenges. Providing appropriate care and support for individuals with dementia and their families living in these communities is especially difficult, and can only be accomplished when the needs of care providers and the context and complexity of care provision are understood. This paper describes formal and informal caregivers' perceptions of the challenges and needs in providing care and support for individuals with dementia living in rural and remote areas of Saskatchewan, Canada.

**Methods:** A mixed-methods exploratory approach was used to examine caregivers' needs. This research was a component of a broader process evaluation designed to inform the initial and ongoing development of a community-based participatory research program in rural dementia care, which included the development of the Rural and Remote Memory Clinic (RRMC). Four approaches were used for data collection and analyses: (1) thematic analysis of consultation meetings with rural healthcare providers: documented discussions from consultation meetings that occurred in 2003–2004 with rural physicians and healthcare providers regarding plans for a new RRMC were analysed thematically; (2) telephone and mail questionnaires: consultation meeting participants completed a subsequent telephone or mail questionnaire (2003–2004) that was analysed descriptively; (3) thematic analysis of referral letters to the Rural and Remote Memory Clinic: physician referral letters over a five-year period (2003–2008) were analysed descriptively and thematically; and (4) examination of family caregiver satisfaction: four specific baseline questionnaire questions completed by family caregivers (2007–2010) were analysed descriptively and thematically.



**Results:** Both physician and non-physician healthcare providers identified increased facilities and care programs as needs. Physicians were much more likely than other providers to report available support services for patients and families as adequate. Non-physician providers identified improved services, better coordination of services, travel and travel burden related needs, and staff training and education needs as priorities. Physician needs, as determined via referral letters, included confirmation of diagnosis or treatment, request for further management suggestions, patient or family request, and consultation regarding difficult cases. One-third of informal caregivers expressed not being satisfied with the care received prior to the Rural and Remote Memory Clinic assessment visit, and identified lack of diagnosis and long wait times for services as key issues.

**Conclusions:** Delivering services and providing care and support for individuals with dementia living in rural and remote communities are especially challenging. The need for increased extent of services was a commonality among formal and informal caregivers. Primary care physicians may seek confirmation of their diagnosis or may need assistance when dealing with difficult aspects of care, as identified by referral letters. Differences between the needs identified via referral letters and questionnaire responses of physicians may be a reflection of the rural or remote context of care provision. Informal caregiver needs were more aligned with non-physician healthcare providers with respect to the need for improved access to additional healthcare professionals and services. The findings have implications for regional policy development that addresses human and other resource shortages.

**Key words:** caregivers, dementia, health services accessibility, health services needs and demand, patient, referral and consultation, survey.

## Introduction

Dementia and its impact on the individual, caregivers and healthcare system have been the subjects of growing interest world-wide<sup>1,2</sup>. Of particular concerns are the considerable personal and socioeconomic consequences related to the extent and duration of dementia-related disability, cost of care, and loss of productivity of those with dementia and their caregivers. Clearly, providing appropriate, effective and efficient services to the increasing numbers of individuals with dementia is a critical healthcare priority.

Early detection and timely diagnosis are paramount, providing individuals with access to appropriate interventions and support services. The value of a comprehensive cognitive and functional assessment, and the importance of educating patients and families about expectations and disease progression have been documented<sup>3-5</sup>, and guidelines for the diagnosis and management of people with dementia in primary care settings are available for formal care providers<sup>6</sup>. Unfortunately, under-reporting of dementia diagnosis and

delayed referrals for dementia-related services are common<sup>7-9</sup>. Population-based screening studies have found that a significant number of individuals with dementia are unknown to their family doctor<sup>10,11</sup>, and that 20–50% of dementia cases are routinely recognised and documented in primary care settings<sup>12-14</sup>. Those who care for a family member with dementia are confronted with heavy psychological and physical burdens<sup>15</sup>. Family caregivers usually lack knowledge of available services and rely on health professionals for information<sup>16</sup>. Obstacles that delay diagnosis may have serious consequences, including delayed access to treatment and services, not receiving critical disease management education and information, and the inability to plan ahead and make important decisions<sup>17</sup>.

With the increasing incidence of dementia with advancing age, the rising prevalence of dementia is of particular concern for rural and remote regions of Canada, which comprise a greater number of older individuals<sup>18</sup>. Rural settings pose particular healthcare and service delivery challenges, necessitating long travel distances to access formal services in urban areas<sup>19-21</sup>. Limited services and under-servicing of



special-needs groups, such as older adults, have been identified as areas of concern for rural, remote and northern Canadian communities<sup>18,22</sup>.

Providing quality care for individuals with dementia can only be accomplished when the context, complexity of care provision, and care providers' needs are understood. This paper describes formal and informal caregivers' perceptions of the challenges and needs associated with providing services, care and support for individuals with dementia living in rural and remote regions in the province of Saskatchewan, Canada.

## Methods

The work reported here was part of a larger research program focused on improving the care of persons with dementia living in rural and remote areas<sup>23,24</sup>. This research represents a component of a broader process evaluation designed to inform the initial and ongoing development of a community-based participatory program in rural dementia care, which included the development of the Rural and Remote Memory Clinic (RRMC)<sup>23</sup>. A mixed-methods exploratory design, comprising four approaches, was used to examine informal and formal caregivers' needs: (1) thematic analysis of consultation meetings with healthcare providers; (2) telephone and mail questionnaires completed by healthcare providers; (3) thematic analysis of referral letters to the RRMC; and (4) examination of family caregiver satisfaction with care prior to the initial RRMC visit.

### Setting

Saskatchewan covers an area of 651 036 km<sup>2</sup> and has a population of approximately 1 million. Health care, including telehealth, is delivered by 13 Regional Health Authorities (RHAs). RHA population densities range from 0.1 to 9.2 (median=1.6)<sup>25</sup>. The three most northern RHAs comprise 44% of Saskatchewan's land mass, and have 3.3% of the population<sup>25</sup>.

### *Thematic analysis of consultation meetings with rural healthcare providers*

Prior to RRMC implementation, research team members travelled to 13 Saskatchewan communities in eight different RHAs that had a telehealth site operated by the provincial network and to two sites operated by First Nations bands<sup>23</sup>. Meetings were held with a variety of healthcare providers and others employed by healthcare facilities or working in the community. The purpose of the meetings was to discuss development of the RRMC and perceived needs related to providing dementia care in a particular community. A research assistant captured discussions verbatim into notes that were then transcribed into a typed record.

### *Analysis*

The record was thematically analysed using a general inductive approach<sup>26</sup>. Thematic analysis, a qualitative data analysis method, was used for identifying, analysing and reporting patterns (themes) within the data. Thematic analysis does not derive from, nor is tied to, a particular epistemological or theoretical position<sup>27</sup>. The record was read and reread multiple times by two authors independently. Key ideas and multiple meanings were considered, and text segments containing meaning units were identified. Recurrent themes were indexed and categorised. Text segments relevant to each category were noted and compared to developing themes. The authors met to discuss and compare the themes and text segments, and findings were verified by consensus and convergence.

### *Telephone and mail questionnaires*

A cross-sectional sample of rural care providers was surveyed regarding their comfort and confidence in providing dementia care, and their continuing education needs.

**Sample:** A convenience sample of healthcare providers who attended the consultation meetings was invited to complete a follow-up questionnaire. Consultation meeting participants



interested in being contacted for additional studies provided their name and contact information, which were entered into a database. Of the 109 non-physician participants in the database, 35 were excluded because they were not healthcare providers, eg senior administrators and clerical staff, and of the 51 physicians in the database, nine were deemed ineligible for participation, eg no longer practising, illness, could not commit to an interview.

**Questionnaires:** Initially, a telephone interview guide was developed for all participants. Subsequently, a mail questionnaire was developed for non-physician healthcare providers because of administration feasibility issues, including inability to leave messages and participants not being available for a phone call. The two approaches used similar closed and open-ended questions, tailored for the two groups, but differing with respect to administration modes. The survey questionnaire and telephone interview guide were examined for face and content validity by research team members, and were pilot tested with healthcare providers. Physician interviews were conducted by a physician. Research staff conducted an initial 28 telephone interviews and the remaining 34 healthcare provider participants received a mail questionnaire.

**Response rate:** Thirty-three physicians completed the telephone interviews (response rate 78.6%), and 28 care providers in management or administration positions and 33 direct care providers completed the telephone or mail questionnaire (response rate 82.4%).

**Analysis:** Descriptive statistics were used to analyse respondents' comfort and confidence with dementia care, service provision and continuing education needs.

**Thematic analysis of referral letters to the Rural and Remote Memory Clinic:** To better understand patterns of needs of rural family physicians, RRMC referral letters were examined. Two hundred and fifty consecutive referral letters from 91 discrete physicians representing the 13 RHAs, over a 5 year period (March 2003 to December 2008 inclusive), were independently descriptively and thematically

analysed by two authors. Each author summarised the content of the referrals, grouping content by similarity, and themes were developed. The authors then met to review the similarities, patterns and consistency of the themes, and consensus was reached regarding the final themes.

**Family caregiver satisfaction:** The last approach involved examining informal caregivers' satisfaction with care received prior to the initial RRMC visit. As part of the RRMC clinic day assessment, a family member or other accompanying caregiver completes a baseline questionnaire (see Morgan et al 2009<sup>23</sup>). Four specific questions from the baseline questionnaire were examined: 'What is the nature of the problem that has caused the most concern?', 'Who decided to seek help for this problem?', 'Are you satisfied up to now with care received for this problem?' and 'Specify why you have not been satisfied up to now with care received for this problem'. All responses from caregivers who completed the questions ( $n=151$ ) were descriptively and thematically analysed by two authors as described previously.

### *Ethics approval*

The research was approved by the Behavioral Research Ethics Committee, University of Saskatchewan (BEH #03-12-19).

## Results

### *Thematic analysis of consultation meetings with rural healthcare providers*

Those who attended the community consultation meetings indicated there was a need for improved referral, management and consultation services for individuals with memory problems, and support services for family members. Broad-ranging specific service needs were identified, including increased access to physicians, specialists and rehabilitation professionals, and long-term care and respite facilities, and day programs. The need for increased services is best represented by the following two quotes: 'There's nothing for seniors, no facility; there's nothing here, no



services for elderly.’ The resultant impact of lack of services on the family and increased family burden was also described: ‘Often families are the long-term care.’ In addition, the need for improved services and better coordination of services were identified as priorities.

Additional themes were related to trying to provide services in remote and rural areas, in particular in areas with high proportions of Aboriginal populations. Examples of travel and travel burden related needs included having to obtain government authority for healthcare-related travel, lack of government or personal funds for travel to healthcare facilities, having to deal with buses that travel to urban centers only on certain days, and cut-backs in taxi services. The need for translation services and more culturally appropriate assessment tools for non-English speaking individuals and their families were also identified. Last, the broad theme of educational needs was evident, and three subcategories were identified across the communities: management of difficult client cases; recognising memory problems; and increased continuing education opportunities.

### *Telephone and mail questionnaires*

**Physician respondents:** The majority of physician respondents indicated their practice was rural, and 35% indicated their practice was remote. The median number of patients with dementia seen per month was six; the range was wide and dependent on whether the physician had responsibility for long-term residents. The median number of new dementia cases diagnosed in the past year was three. A large majority of physicians (90%) reported using a standardised mental status test, with 90% of these respondents using the Mini-Mental State Exam (MMSE). Thirty-two percent of respondents reported using published clinical guidelines to diagnose dementia.

About half (52%) of the physicians reported being fairly comfortable with diagnosis and management of patients with dementia, while 10% reported being extremely comfortable. Thirty-five percent indicated being extremely comfortable with explaining the diagnosis and prognosis of Alzheimer’s

disease (AD) and other dementias to patients and their families, and 39% reported being fairly comfortable. With respect to dealing with driver’s license issues, 19% reported being very comfortable and 32% reported being fairly comfortable. A majority (83%) of physicians reported that they would like more access to continuing education opportunities on the topic of dementia, particularly diagnosis and initiating treatment. Workshops were the preferred format, and 29% indicated it was extremely important for continuing education opportunities to be offered locally.

Almost half (48%) of physicians reported support services available to persons with dementia and their caregivers in their community to be adequate. Sixty-five percent of the physician respondents ( $n=20$ ) indicated that more care facilities and programs would enhance currently available services. About one-third ( $n=10$ ) indicated that additional healthcare professional services, such as support services and counselling, physical therapy, occupational therapy, weekend nursing services, geriatrician expertise, and psychology, were needed.

**Non-physician healthcare provider respondents:** Of the 61 non-physician respondents, 47.5% ( $n=28$ ) were in management or administration positions, and 50.8% ( $n=33$ ) were involved in direct patient or client care. More than half indicated that their practice was rural, 49% indicated their practice was remote, and some endorsed both rural and remote. One-quarter of the respondents reported being uncomfortable in their ability to recognise the signs and symptoms of AD and other related dementias, 38% were neutral, and 36% reported being fairly or extremely comfortable. Similar findings were reported for comfort and confidence in providing support and guidance to individuals with dementia or their families, with 31% being fairly comfortable and 14% extremely comfortable. Ninety-one percent of respondents reported wanting more continuing education on the topic of dementia, with preferred formats being workshops and telehealth, and 80% indicated that it was extremely important that educational opportunities be offered locally.



In contrast to the physician respondents, less than one-fifth (19.3%) indicated that support services available to persons with dementia and their caregivers in their community were adequate, and the following were identified as needs: (1) healthcare facilities and services, such as respite, home care, day programs, long-term care facilities, and programs for early stage patients; (2) family support services, including support groups, social work, and volunteer psychogeriatric nursing services; (3) staff training; and (4) other – early diagnosis and treatment, public education, and a team approach to care.

**Thematic analysis of referral letters to the Rural and Remote Memory Clinic:** Of the 250 referral letters analysed, 157 (62.8%) included either a stated diagnosis of dementia or evidence that the physician suspected a dementia, as indicated by a MMSE score, a Functional Assessment Questionnaire score, or a notation that the patient was taking a medication for dementia. There was wide variation in the extent, and sometimes the quality of information (eg for triaging purposes) provided. Referrals ranged from a one-line statement such as ‘Please see this patient for assessment’, to a lengthy family and medical history, with complete clinical work-up. Fifty-three percent of the referral letters were general requests for assessment, evaluation or consultation, and 25% were requests for management. A small proportion of these management referral letters were a specific request, primarily for medication and medical treatment consultation.

Needs, as identified through the referral letters, were categorised into the following four broad themes. Representative quotes that highlight the needs are provided.

**Confirmation of diagnosis or treatment:** Confirmation of diagnosis or medical treatment was being sought in about 25% of referrals. In some cases, referrals reflected the need for an opinion about what was causing the patient’s problems. In other cases, the family physician had made the diagnosis and indicated the treatment option under consideration, and needs included a second opinion to validate a dementia

diagnosis, the specific type of dementia diagnosis, or confirmation regarding the proposed medications:

*I am not sure of the diagnosis and would be grateful for your involvement.*

*I would appreciate it if you would kindly assess her and advise if she is a candidate for Aricept.*

**Request for further management suggestions:** In some cases, a specific dementia diagnosis had been made by the family physician and pharmaceutical treatment initiated prior to referral. Needs in these instances were related to receiving information about additional treatments that could be implemented to manage the patient overall or to manage specific impairments, such as behavioral symptoms. These referrals were typically related to non-response to treatment, worsening of symptoms, or disease progression:

*She was tried on Aricept as well as Exelon with a poor response . . . MMSE has been declining over the last few months. I would appreciate your evaluation of this patient in this regard.*

*Is there anything further that can be done for him?*

*Your assistance with further management would be appreciated.*

**Patient or family request:** As described previously, in some instances a dementia diagnosis had been made and treatment had been initiated by the referring physician. However, rather than reflecting worsening of symptoms or disease progression, the referral reflected a need to respond to a patient’s or family member’s specific request for additional assessment and in particular, a referral to the RRMC:

*His wife is very interested in other treatment options for his Alzheimer’s disease.*





*MMSE is 14/30. I started Reminyl 4 mg BID and increased it to 8 mg already. Daughter wants assessment.*

*Progressive dementia. On Aricept. Patient requested referral.*

**Consultation regarding difficult cases:** The last category of need included requests for assistance with managing complex patient cases. Issues causing case complexity leading to the referral were typically related to disease progression, development of new symptoms, or worsening of symptoms:

*She presented with primary progressive aphasia and now has developed cognitive problems . . .*

*Tried a course of Aricept. Her children think it is making her worse.*

**Family caregiver satisfaction:** Not surprisingly, memory problems caused the most concern for family caregivers ( $n=92$ ), followed by agitation or confusion ( $n=17$ ), language or comprehension problems ( $n=10$ ), and concentration or thinking problems ( $n=9$ ). Other problems identified as causing the most concern were behavioral symptoms, such as emotional changes ( $n=9$ ), personality changes ( $n=9$ ), lack of motivation or energy ( $n=4$ ), and hallucinations ( $n=3$ ). Family caregivers also reported health issues ( $n=13$ ), balance, mobility and gait difficulties ( $n=7$ ), and difficulties with activities of daily living or instrumental activities of daily living ( $n=7$ ) as the problems causing the most concern.

In response to the question 'Who decided to seek help for this problem?', 53.9% of the caregivers reported they had initiated seeking help for the problem. The remaining responses indicated the referrals were initiated by the patient (20.0%) and family physician (23.4%). Only two indicated that other healthcare professionals prompted the referral. Thirty-one percent of informal caregivers expressed not being satisfied with the care received prior to the RRMC assessment. Four themes related to lack of satisfaction with care prior to the RRMC visit were extracted and representative quotes are included.

**Perceived lack of care, inadequate care or inappropriate care:** Informal caregivers often indicated they felt the care provided prior to the RRMC assessment was not appropriate or sufficient. Patients receiving a medication that seemed to be ineffective, healthcare professionals not adequately addressing specific patient problems, and informal caregivers needing to find information themselves were often reported.

*Because writing another prescription isn't the answer . . .*

*Doctors – specialists – they didn't seem to agree. They keep changing medications.*

*He was given pills, but there was no follow-up.*

*I've had to get my own information and have asked the doctor to act on it.*

*There really was no care, particularly dealing with his memory.*

**Family physician or other healthcare professional minimised the problem:** Informal caregivers noted problems experienced by the patient (eg memory) were often dismissed by healthcare professionals. Informal caregivers reported being told there was no cause for concern or that the problems their loved one was experiencing were considered 'normal' ageing:

*B's doctor doesn't seem to recognise this as a problem*

*Drs and Mental Health specialists . . . did not take the problem seriously.*

**Wait times or amount of time to diagnosis:** Many caregivers commented negatively on the wait time to get appointments with healthcare professionals, to have diagnostic testing (eg imaging) completed, and to get answers to their questions. In addition to access issues, caregivers reported having multiple appointments without getting the information they needed or having an understanding of what was causing their loved one's identified problems. These



multiple visits added to the amount of time to receive a diagnosis:

*We have been seeking help for over a year.*

*Long wait lists, difficulty getting any tests done.*

**Lack of diagnosis:** Informal caregivers reported frustration with not receiving a 'name' for the problem the patient was experiencing or for the behaviors the patient was exhibiting. Difficulties and delays were experienced in getting a specific diagnosis, and informal caregivers felt things weren't being done or being done quickly enough to determine what was wrong with the patient:

*I (we) have not had an answer as to why M has not been well, what has caused his not feeling well and memory loss.*

## Discussion

The multi-pronged approach used to examine areas of need for rural and remote dementia care in Saskatchewan, Canada, incorporated a broad continuum of care contexts and included formal and informal caregivers' perspectives. Not surprisingly, for both physicians and family caregivers the primary reason for referral was suspected memory problems. However, the motivation and rationale for referral differed. In some cases, physicians were responding to family members' requests for further evaluation. Informal caregivers reported they were often the ones who initiated the referral, suggesting that even when primary care medical management is perceived as appropriate, family members may feel the need to ensure the best care avenues are being pursued for their loved one. In other cases, a specific dementia diagnosis had been made and the physician had already initiated pharmaceutical treatment prior to referral. This finding suggests primary care physicians may be seeking confirmation of their diagnosis or may need assistance when dealing with difficult aspects of care, such as assessment of driving competence or medication prescription.

About two-thirds of physicians who participated in the telephone interviews indicated being fairly or extremely comfortable with the diagnosis and management of patients with dementia, and about half reported being fairly or very comfortable dealing with driver's license issues. These findings are similar to those reported in other jurisdictions. For example, 64% of UK general practitioners described themselves somewhat or very confident about their ability to diagnose dementia, and 32% felt somewhat or very confident about communicating management<sup>28</sup>. The main difficulties identified by these practitioners included talking to patients about the diagnosis, responding to behavior changes, and coordinating support services<sup>28</sup>. Responding to behavior changes was also identified in the analyses of physician referral letters.

The differences between needs identified through the referral letter (about half of the referrals were general requests for assessment, evaluation or consultation) and the telephone interview responses (about half of the physicians indicated feeling fairly comfortable with diagnosis and management of dementia) may be a reflection of the data collection methods or the context of care provision. It is possible that physicians may be more (or less) open or detailed in a telephone interview being conducted by another physician, rather than in a written referral document requesting specialist services. As well, the referral letters were linked to specific patients, whereas in the interviews physicians were asked about their comfort and confidence in diagnosis and management of dementia in general. The degree of overlap in samples between the physician referral letter and telephone survey components is not known, but is likely very small. This may account for differences in responses found between the two methods.

The rural or remote practice setting is unique and highlights the complexity, richness and challenges of therapeutic boundaries. Rural settings are highly interdependent and interconnected. Uncertainty and lack of agreement within and among rural health professions regarding the appropriate course of action that should be taken when problems arise have been reported in the literature<sup>29</sup>. This uncertainty is





often exacerbated by the intertwined health professional–patient relationships in rural settings – for example, the patient may be the healthcare provider’s mechanic, minister or postal carrier<sup>30</sup>. Familiarity between healthcare providers and their clients is often a prerequisite to developing trusting relationships and is often unavoidable in the rural context<sup>31,32</sup>. Whether or not and to what extent close personal relationships or the relative intimacy of rural or remote life played a role in the different findings could not be determined and should be further explored.

Both informal and formal caregivers identified a need for increased and improved services for people with dementia living in rural and remote areas. Although the number of respondents indicating that services were adequate differed between physicians and other healthcare professionals, both groups identified the need for healthcare facilities and care programs. Informal caregiver needs were more aligned with non-physician care providers with respect to the need for improved access to physicians, specialists and healthcare professionals who can provide additional care services, such as physiotherapists and occupational therapists. It is possible that the physician participants interpreted the question about support services differently from the other healthcare providers. However, the findings may be a reflection of the amount of time primary care physicians, versus other healthcare providers, are able to spend with patients and their family, due to the nature of the healthcare system and the context of providing medical care in rural and remote areas. Uneven distribution of physicians, nurses, medical specialists, healthcare professionals and other care providers, and a payment system that does not reflect the time needed for assessment, are real issues in providing services, particularly in rural and remote areas. As well, physicians have a different role in caring for patients and families – this could have resulted in the different perspectives regarding adequacy of supports. Non-physician healthcare providers may be more closely involved in post-diagnostic support for patients and families and may be more aware of the challenges of accessing supports, and the consequences when the supports are not available.

The lack of diagnosis and long wait times for services identified by the informal caregivers have been found to be common concerns in previous studies<sup>33,34</sup>. Speechly et al reported that it took almost two years to contact a healthcare professional and roughly 2.7 years from first symptom onset to receiving a diagnosis<sup>33</sup>. The mean time from first contact with a healthcare professional to arrival at a memory assessment service was reported to be almost three years in a UK study<sup>34</sup>. Clearly these types of delays can cause much frustration and anxiety for patients and their family members. The direct quotes from family caregivers highlighting a lack of satisfaction with care received prior to the RRMC visits are very telling. Although these quotations may appear harsh at first glance, it is important to keep in mind that the quotes are a reflection of the frustration experienced by informal caregivers in accessing adequate services and answers to their questions, in particular when human resources and facilities are stretched beyond their limits in rural and remote areas.

Another difference between physicians and other healthcare providers was related to continuing education needs. Physician respondents did not view local access to continuing education as a priority, whereas non-physician respondents indicated a stronger preference for opportunities offered locally. Physicians may be more easily able to access educational opportunities offered at a distance or may have more access to or may be more comfortable with web-based learning, compared to other healthcare providers. Physicians are likely to have more professional autonomy to take the time away from clinical practice for travel, as well as greater resources for travel and continuing education opportunities in general. Access to continuing education can affect job satisfaction<sup>35</sup> and influence the retention of health professionals in rural areas<sup>36</sup>. In light of the findings, continuing education opportunities targeting the specific needs of those involved in providing dementia care in rural and remote settings are recommended. In addition, general access issues and service delivery shortages need to be addressed. Funding programs should be established for non-physician formal caregivers and programs that advance rural and remote healthcare professional recruitment and retention strategies, similar to those targeted to Saskatchewan physicians.



Formal care providers reported a desire for more information about dementia assessment, management, and family support strategies. As reported by others, the non-physician healthcare providers reported feeling uncomfortable in their ability to identify signs and symptoms of AD and other related dementias<sup>37-40</sup>, highlighting the need for further education using acceptable and feasible strategies. Areas of need as indicated by referral letters also included management and family support strategies, as well as differential diagnosis, confirmation of diagnosis, and consultation regarding complex cases. These identified areas provide a focus for developing continuing education programs and strategies for healthcare professionals caring for people with dementia living in rural and remote areas. With the advances in web-based technology both for personal use and for healthcare delivery (eg telemedicine), it is possible to structure continuing education using non-traditional teaching strategies.

The Canadian Consensus Guidelines propose that most patients and families can be assessed and managed by a primary care physician<sup>41</sup>, yet only half of the physician respondents reported they were 'fairly comfortable' with diagnosis and management. Some studies suggest up to 50% of dementia cases are not diagnosed by primary care physicians and that primary care physicians do not consistently apply recommended assessment procedures<sup>12-14</sup>. Others have reported the number of accurately identified cases to be high<sup>4</sup>, and studies suggest primary care physicians can make a dementia diagnosis with reasonable accuracy if specifically prompted<sup>42</sup>. In a paper describing what general practitioners want from specialist services in managing people with dementia, Williams (2000) reported the following to be important: receiving confirmation of diagnosis and prognosis for both the general practitioners and family; assistance with the special needs of young dementia patients; helping caregivers accept the diagnosis; assistance with driving cessation recommendations; and assistance with symptomatic treatment and planning care<sup>43</sup>. Thematic analysis findings of referral letters align with many needs identified by Williams<sup>43</sup>. However, it is not clear whether the needs reflected in the findings represent feelings of inadequate

training in dementia care, lack of confidence in managing people with dementia, concern over the implications of a dementia diagnosis for patient and family, whether primary care physicians feel the diagnostic task and disclosure of the dementia diagnosis belongs to specialists, or other contextual factors. Further research is warranted and is underway.

## Conclusions

This study focused on understanding formal and informal caregivers' perspectives of the challenges, issues and needs in providing care for people with dementia living in rural and remote regions of Saskatchewan, Canada. Informal and formal care providers' needs were similar to those previously reported: increased availability and types of services, care facilities, and programs; increased access to primary care providers, specialists, and rehabilitation professionals to address wait times for diagnosis and management; and continuing education related to recognising signs and symptoms of AD and other dementias, and the diagnosis and management of people with dementia. Non-physician care providers were more aligned with informal caregiver regarding the need for improved access to additional healthcare professionals and dementia care services. Referral letters indicated primary care physicians sought confirmation of their diagnosis and assistance with difficult aspects of care. Although preferred modes of delivery differed, both physicians and other healthcare providers indicated a need for more continuing education focused on dementia assessment, management and family support strategies. Those directly involved in dementia care, policy makers and governments are challenged to develop innovative health service delivery models that meet the diverse needs of formal and informal care providers and address human and other resource shortages within the unique context of rural and remote care.

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