

NOTICE: this is the author's version of a work that was accepted for publication in Maturitas. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in Maturitas, 68, 17-33. doi: 10.1016/j.maturitas.2010.09.008

TITLE: Dementia care in rural and remote settings: A systematic review of formal or paid care

AUTHORS: Debra Morgan, Anthea Innes, Julie Kosteniuk

ABSTRACT

Objectives: The purpose of this review is to critically evaluate the available evidence from the published scientific literature on dementia care and service provision in rural and remote settings from the perspective of formal/paid caregiving, in order to assess the current state of knowledge, identify policy and practice implications, and make recommendations for future research.

Methods: A systemic review of the literature indexed in ISI Web of Knowledge, PsychInfo, Medline, Healthstar, CINAHL, EMBASE, and Sociological Abstracts was conducted. Data were extracted from papers meeting inclusion criteria: peer-reviewed papers that focused on dementia or Alzheimer's Disease (AD), examined care or service provision in relation to persons with AD or dementia, and relevant to rural or remote care or services.

Results: The search identified 872 articles for review, reduced to 72 after removing duplicates and articles not meeting criteria. Of the 72 remaining, 46 are included in this current review focusing on formal or paid care. A future review will focus on the 26 studies on informal/unpaid care. Six themes that correspond to the current state of knowledge in rural dementia care in the 46 included studies were: diagnostic processes, service provision, service models and programs, staff education and support needs, use of technology, and long-term care.

Conclusions: Despite the growing body of evidence over the 20 years covered by this review, much of the research is descriptive and/or based on small sample sizes, and distributed across the care continuum. Hence the body of evidence on which to base policy and program decisions remains limited. More research is needed that would support the development of comprehensive rural dementia care models.

KEYWORDS: rural, remote, dementia, Alzheimer's disease, formal care, services

1. Introduction

The term "dementia" is used to describe a large class of disorders characterized by progressive decline in cognitive abilities, including loss of memory, judgement, reasoning, as well as changes in mood, behaviour, communication, and functional ability. Alzheimer's Disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia are the most common subtypes. At present there is no cure for dementia and dementia remains the leading cause of dependency and disability among older people [1].

The prevalence of dementia is estimated at 35.6 million people worldwide in 2010, and in the absence of any significant new scientific discovery, prevalence rates are estimated to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 [1]. Much of the global increase is attributed to increases in the number of people with dementia in low and middle income countries [1]. The worldwide cost of dementia was estimated to be US\$315 billion per year in 2005 [2]. The cost of care is projected to soar as a result of increasing prevalence and decreased availability of family and other carers [3].

A growing number of countries have developed, and some cases implemented, national dementia strategies that outline current and projected incidence and prevalence rates, and identify approaches for developing and improving dementia services. The rise in numbers of people with dementia is related to the “graying” of the population, as prevalence roughly doubles every five years over age 65 [1]. Internationally, rural areas are aging faster than urban areas, leading to high proportions of older people in rural communities [4-6] and thus more people at risk for dementia, yet rural areas are characterized by their limited access to health and social services.

In an early review paper of 19 studies focussing on dementia in rural settings published in 1996 [7], the authors concluded that further research was needed to fill the information void for public health policy-makers. Ten year later Innes et al. [8] noted that the provision of health and social care services to people with dementia and their carers living in rural and remote settings was neglected globally, and that the challenges of meeting the needs of people with dementia was compounded by the difficulties of providing and accessing services in rural areas. Urban models of care are often applied to rural areas but do not account for access issues related to distance from services. More recently, an evidence-based review of service needs and delivery following dementia diagnosis [9] identified rural dementia care as an issue and recommended further research aimed at improving understanding of dementia, dementia services, and social inclusion in relation to rurality.

The purpose of this review is to critically evaluate the available evidence from the published scientific literature on dementia care and service provision in rural and remote settings as it relates to formal or paid care, in order to assess the current state of knowledge, identify policy and practice implications, and make recommendations for future research. Given the growing emphasis on chronic disease management and patient-centred care, and the need to understand the continuum of care in the rural context [10] this review will include research related to all stages from early assessment and diagnosis to end-of-life care.

2. Methods

2.1 Search strategy

A comprehensive search of the literature was conducted between January 22, 2010 and January 27, 2010. Seven databases were searched: ISI Web of Knowledge, Healthstar, Medline, PsycInfo, EMBASE, CINAHL, and Sociological Abstracts. The following search terms were employed for all databases: (dementia or alzheimer*), (rural or remote), and (care* or support or service or nurs* or tele*). An asterisk indicates that all terms that begin with that root were included in the search. The search was limited to studies published in the English language between 1990 and 2010.

2.2 Inclusion criteria

The studies considered for inclusion were published peer-reviewed original articles. Dissertations, editorials, book chapters, book reviews, letters to editors, and commentaries were excluded from review. Studies were considered for review if they met all of the following criteria: focused on dementia or Alzheimer's disease, examined care or service provision in relation to persons with dementia or Alzheimer's disease, and were relevant to rural or remote care or service provision. Only studies that involved formal or paid care were included in this review.

2.3 Data extraction

The data were extracted from each study by one reviewer, JK, and verified by DM and AI. Extracted data included details regarding the sample, study objective, definition of rural/remote, care/service providers, major findings, and study recommendations.

3. Findings

The database search identified 872 articles for review. After reviewing the abstracts, 510 duplicates and 34 that were not from peer-reviewed original articles were removed. One reviewer, JK, reviewed all of the remaining 328 abstracts, and DM and AI each reviewed half of the remaining abstracts. On this basis, 183 abstracts were excluded because they did not meet the inclusion criteria. All three reviewers reviewed the full text of the remaining 145 papers. Of these, 73 papers were excluded because they did not meet the inclusion criteria. A total of 72 studies met our inclusion criteria; 46 studies are included in this present review focusing on formal/paid care; 26 studies will be included in a future review of papers that focus on informal/unpaid care.

Papers were included in the current review if the study sample was primarily formal or paid caregivers and/or the study objectives related primarily to formal caregivers or services. Six themes were identified in the 46 studies included in this review: diagnostic processes, service provision, service models and programs, staff education and support needs, use of technology, and long-term care. Studies are grouped by theme in Table 1, along with country; study method, sample, and objective; definition of rural or remote; and major findings.

Insert Table 1 about here

No definition of rural or remote was provided in 22 of the 46 articles. Due to lack of detail provided about definitions and criteria for sampling, it was difficult to categorize the types of definitions used. Four articles appeared to use a standardized definition based on national census divisions, government departments, or health surveys. In some cases authors developed their own criteria for inclusion based on previous research or the study purpose (ranging from populations of less than 2,000 to less than 25,000 people) or used distance from an urban centre. In many cases it appears that a convenience sample was used and the population and/or population density of the town or county was reported. In several cases a general description such as "rural," "farming," "non-urbanized," or "nonmetropolitan" was the only information reported.

3.1 Diagnostic Processes

This theme (10 articles) includes formal caregiver knowledge and perceptions of access to diagnostic services and caregiver supports, general practitioner (GP) assessment and referral, and memory clinic models.

3.1.1

Caregiver knowledge and perceptions

Three articles focused on the dementia-related beliefs, knowledge, and confidence of primary care providers. A study of GPs in rural New South Wales [11] found that GPs ranked dementia third out of eight mental health conditions, in terms of their confidence in diagnosis and treatment. A US study of urban and rural clinicians [12] including primary care physicians, specialists, advanced practice nurses, and physician assistants, found no significant differences in knowledge, confidence, and beliefs between rural and urban clinicians. In the US [13], rural primary care providers were sceptical about the effectiveness of current treatments, and substituted terms such as ‘memory difficulty’ for Alzheimer’s Disease and dementia due to their perceived stigma. Furthermore, rural care providers believed that the family played a key role in early diagnosis, and that a good provider-family relationship facilitated patient care [13].

Three articles examined GPs’ dementia service access and perceptions of such access. Cahill et al. [14] reported that although rural GPs in Ireland perceived that they had poor access to diagnostic services such as CT scans and MRIs, urban and rural GPs reported similar time delays in accessing secondary services. In a US-based study, Meuser et al. [12] found that rural clinicians were less likely than urban clinicians to characterize the education and support services of the Alzheimer’s Association as accessible. Teel [13] found that although all of the rural primary care providers in their US-based study had access to the necessary lab and imaging equipment for diagnosis, specialists and community support resources were largely inaccessible due to travel distance, limited availability locally, and long wait times.

3.1.2 *GP Assessment and referral*

Four articles investigated screening and assessment by rural primary care providers. A study of a rural county in Ireland [15] suggested that the greater prevalence of dementia among persons over 75 years reflected the identification of dementia during GPs’ annual health checks of this age group. A US study [16] reported rural family physicians rarely conducted formal mental status assessments for diagnosed patients with dementia. In contrast, Teel [13] found that most rural primary care providers in a US-based study administered the MMSE when assessing patients with possible dementia. Also in the US, Meuser et al. [12] reported that the frequency of use of the MMSE and other dementia screening tools did not significantly differ between rural and urban clinicians.

Investigations of GPs’ referral practices found that patients presenting with dementia were the third most referred patients by rural GPs to mental health specialists, after patients presenting with depression and anxiety [11]. An Australian-based study [17] reported that urban GPs were more likely than rural GPs to refer patients with suspected dementia to specialists, and rural GPs were more likely than urban GPs to diagnose dementia themselves. This study also suggested that rural GPs practiced more autonomously than urban GPs, due to barriers to specialist referrals including travel and lack of access [17]. In the US, Meuser et al. [12] reported that a greater

proportion of urban than rural clinicians referred patients and families to the Alzheimer's Association.

3.1.3 Memory clinic models

Three studies reported on memory clinics and their role in early diagnosis and management of dementia. Cheung & Strachan [18] surveyed all of the publicly-funded memory clinics in New Zealand, to explore their funding structure and staffing levels. Eight of the 21 health districts had a memory clinic, with only one serving a population of fewer than 10,000 persons. Five clinics had dedicated funding, raising questions about sustainability. The authors pointed out the inequality of access for early diagnosis and management in different parts of the country and identified resource issues and availability of expert staff as barriers in establishing memory clinics in smaller regions. "Innovative service delivery models such as telemedicine and mobile clinics will therefore need to be considered in rural and remote areas" (pg. 246). For example, a "Memory Van" has been implemented in two regions to provide free memory testing and information on dementia and services.

Two articles [19,20] reported on the development, operation, and evaluation of a Rural and Remote Memory Clinic in western Canada. The one-stop interdisciplinary clinic aimed to reduce repeated travel and shorten time to diagnosis by coordinating assessments on one day and using telehealth videoconferencing for pre-clinic assessment and follow-up. Morgan et al. [19] described the clinical measures used by the team to assess patients and caregivers, the program evaluation strategy, and demographic characteristics of the first 137 patients. Preliminary results indicated that the clinic is a feasible and acceptable approach. Crossley et al.[20] reported on the unique opportunities for interprofessional education, research, and clinical collaboration in the clinic.

3.2 Service Provision

Seven articles reported on aspects of service provision for individuals with dementia and their caregivers, from the perspective of formal providers. These articles focus on two topics: service needs, gaps, and barriers to service use; and service delivery strategies.

3.2.1 Service Needs, Gaps, and Barriers to Use

In the US, Shope et al. [21] found that information and referral agencies in urban settings were more likely to report a physician specializing in elder care within 50 miles; rural agencies were more likely to report client inaccessibility to services and lack of transportation. Also in the US [22], rural providers and community leaders identified caregiver needs for dementia care information and education regarding the characteristics, diagnosis, and management of dementia, and the availability of community support services. Distrust of outsiders, a strong sense of family privacy, and stigma associated with dementia were identified as barriers to referral and use of services. Similarly, another US-based study [23] identified self-sufficiency, social isolation, distrust of outsiders, and stigma as issues in serving rural African-American and Latino communities. The only study examining long-term care, conducted in a rural county in Ireland [15], found that 52% of people with dementia from the main town were living in a nursing or residential home compared to 36% of those in the rural area of the county.

A study of service providers in rural Scotland [8] identified four key problems in providing quality dementia services: distance and lack of transport, cost of service for the user, lack of choices in services, and a shortage of skilled staff. In a follow-up study [24], three themes were identified related to difficulties and opportunities facing nurses working in rural and remote areas: access to and availability of services, quality of services, and joint working practices. Nurses or self-referral were the key routes to accessing services, suggesting that nurses need to be aware of available support services and sensitive to how social contexts and value systems impact an individual's ability to access services. Service coverage was deemed inadequate by 72% of respondents; in addition to the gaps identified by Innes et al, additional needs included services for people living at home, specialist services for dementia, long-stay care provision, and specialist training and recruitment.

In a study of front line managers and services users in three English rural counties [25], reported challenges included patchy services, lack of a funded national strategy, unresolved debate regarding desirability of integrated vs. separate services for people with dementia, limited access to specialist teams, and lack of services for people with early onset dementia and minority ethnic groups. The authors recommended maintaining people at home for longer, implementing person-centred care and caregiver support, and creating partnerships and sharing of specialist services.

3.2.2 Service Delivery Innovations

Three quarters of the service providers in a rural Scotland study described innovations aimed at addressing availability and accessibility gaps in dementia services [8]. Strategies included providing transport, either by the service provider or in partnership with other organizations; developing outreach services and in-home services; and working with other providers in their geographical area. Study findings highlighted the issues of balancing the need for timely specialist services vs. improving the capacity of mainstream services, identifying which services could be provided locally vs. those where it is unrealistic to expect local availability, and examining the pros and cons of generic vs. dementia-specific service provision.

In the US [23], service providers working with rural African-American and Latino communities described four general strategies they used to address barriers to service delivery, which recognized the cultural beliefs of these communities. These innovations included an emphasis on services as complementing and supplementing family care, an emphasis on social aspects of care, developing strategies to help families obtain better information about dementia, and tailoring services to meet the unique needs of their client population.

3.3 Service Models and Programs

Six articles reported on programs and models of health service delivery, focusing primarily on case management and referral services. One paper included here [26] is primarily a position paper and another [27] described driving assessment. Memory clinic models designed to serve rural areas, which are also relevant to this section, were discussed earlier in relation to diagnostic processes.

The article by Buckwalter [26] argued for the development and evaluation of innovative dementia care services for rural US communities. Areas for improvement included public education about the value of accurate diagnosis, post-diagnostic support and education, case

management, expanded range and coordination of services, outreach programs, information and dissemination mechanisms regarding available resources, training of health care providers, and programs that are sensitive to rural values and beliefs. Fox et al. [27] surveyed geriatricians working in rural and urban Aged Care Assessment Teams (ACATs) in Australia regarding determination of fitness to drive in dementia patients. Rural ACATs were less likely to assess patients as unsafe to drive and more likely to prescribe restricted licenses, and to conduct follow-ups less frequently.

3.3.1 Case management and referral

Four articles reported on case management and referral programs in rural settings. Two of the four articles provided descriptions of models or programs that have been implemented and their successes and challenges [28,29] and two reported results of program evaluations [30,31].

Schraeder et al [28] used a randomized control trial to evaluate a case management model providing in-home nursing assessment and community-based services to Alzheimer's disease patients and caregivers in rural US communities. Treatment-control group comparisons were not reported but program success was attributed to monitoring of needs, service coordination, and maximizing the informal support system.

Two demonstration projects in rural Maine were designed to improve service access and coordination [29]. A respite program provided caregivers with resources to purchase services in-home, at a day centre, or overnight in a nursing home. Services could be purchased from an agency, neighbour, or friend in any combination. The Geriatric Dementia Evaluation Program offered in-home dementia assessment to rural persons in one U.S. state, as well as in-home assessment of caregiver depression, service referrals, and information and education. The program met the needs of rural persons without access to such services, as well as those who did not want to travel to a physician. The authors describe what has worked and not worked in implementing these programs [29].

The CARE Program [30] used a consumer-directed family consultant model to deliver dementia-specific services to caregivers from rural and minority communities at three sites in North Carolina. Success in developing local networks of dementia-specific services was linked to increasing awareness and coordination of services, cultural sensitivity, and developing partnerships with local agencies to leverage new funding. To address the social barriers (e.g., stigma, independence) to delivery of mental health services in a rural US state and the lack of specialist services, Vissing et al. [31] evaluated a partnership model in which organizational and professional resources were imported from outside the rural area, and family liaison and community organization were provided locally. Services included case finding, assessment, referral, care management, and training for formal and informal caregivers. A limited-term partnership was recommended for future programs.

3.4 Staff education and support needs

Staff education and support needs were the key focus of six papers, but the need for education was recommended in a further 10 papers discussed under other themes. Two US papers described a train-the-trainer approach to education. Coogle [32] reported on training provided for African America family caregivers in Virginia, arguing that trainers need to be culturally

sensitive, and that the selection of trainers from existing community leaders is essential for success. Connell et al. [33] described an information dissemination program (including train-the-trainers approach) about dementia, targeted at healthcare professionals (27 trainers and 3276 learners) in rural Michigan. Trainers who were healthcare professionals were found to be more effective at implementing learning than trainers who were administrators. They argued that projects need 18 months to allow for dissemination and implementation and that the views of the targeted learners should be taken into account when developing the curriculum. Knowledge about dementia increased after participation in this study [33], a finding also reported by Rankin et al. [34] in their education programme, Training Rural Alzheimer's Networking Services for Education and Referral (Transfer) involving 125 health professionals. In this US-based study Rankin et al. found that health care providers learned more than social service providers, and health care providers continued to use the materials 6 months after the programme. The Rural Alzheimer's Education Project [29] provided training to GPs by an interdisciplinary team that traveled to rural health centres in Maine.

Although not dementia specific, a finding from Goins et al.'s [35] exploration of the knowledge, educational needs, and continuing educational preferences of rural health care providers regarding geriatrics was that rural health care providers wanted to learn more about Alzheimer's disease/dementia. The preference was for local training rather than distance learning. Goins et al. [35] suggested that geriatric education should be incorporated into undergraduate education programmes to provide workers with a basic grounding in dementia care. The only article to discuss learning opportunities for students in the health professions, Crossley et al. [20] described the training of clinical psychology practicum students, predoctoral interns, and graduate students in a rural memory clinic in Canada. Students were integral to the clinic and benefitted from interdisciplinary partnerships in conducting their projects. The clinic also facilitated capacity building related to clinical training and provided first-hand experience of rural dementia care issues by students.

3.4.1 Distance education models

The use of technologies to promote education and learning was discussed in two US studies. Bellaver et al. [36] were one of the first to discuss the use of telecommunication strategies to provide continuing education programmes for nurses working in long-term and home health care in rural areas as a way to overcome professional isolation. Nurses in their study reported interest in a telephone consultation service on the topics of family and community care, behaviour management, and diagnosis. Paul et al. [37] reported on a training opportunity offered via a 90-minute videoconference to 23 communities. The program was targeted at formal care workers and family carers, but also available on public television throughout a U.S. state. They argued that telecommunications technology can be used to provide educational information to rural caregivers, and to facilitate interaction between healthcare providers and rural caregivers who were happy to attend a joint training opportunity that allowed them to participate from their individual rural locations. Based on the positive feedback from family carers and paid care workers they concluded that education, healthcare, and social service agencies should partner to create teleconferences for all rural caregivers.

3.4.2 Education recommendations across themes

Six papers relating to service use advocated the need for further education and training. A lack of training and education opportunities was reported for rural service providers [8,23] with the independent sector reported as having particular training difficulties in an English study [25]. Glueckauf et al. [22] argued for a partnership approach to education about the diagnosis and management of Alzheimer's Disease, while Gilmour et al. [15] argued for training targeted at GPs. Vissing et al. [31] supported a partnership approach between educators and rural agencies, arguing that a better understanding of differences in rural and urban service provision is required.

Two US-based papers primarily concerned with diagnostic processes also argued for the need for more education. Teel et al. [13] argued that community education can be useful for educating the public about dementia as well as nurses and other health care professionals. They suggested that outreach interventions in rural communities should target consultation and education. Meuser et al. [12] stressed the importance of delivering dementia-specific continuing education to rural clinicians that would be perceived as accessible.

Two long-term care papers reported on education needs. Neville et al. [38] found that the continuing education preferences of Australian aged care facilities staff included face-to-face training, and continued support after program completion. They argued that the barriers to continuing education for aged care facilities staff included cost, lack of information, travel distance, and staff shortage to replace staff attending continuing education programs. In Canada Morgan et al. [39] found that one-third of nursing aides working in rural nursing homes with dementia Special Care Units (SCUs) and one-half of nursing aides working in rural non-SCU nursing homes had not attended dementia specific continuing education programs. Barriers to attendance included cost, lack of programs, and the requirement to attend on their own time. They argued that providing adequate dementia care training for nursing aides may decrease job strain and improve confidence and suggest that on-site rural delivery or internet delivery may address the difficulties rural staff have in accessing education programmes.

3.5 Use of Technology

Six studies reported on the reliability, validity, and feasibility of assessment tools administered via telehealth, and five studies reported on dementia diagnosis, management, and consultation via telehealth. Education and training using distance technology were described in two studies [36,37] discussed under the staff education theme.

3.5.1 Reliability, validity, and feasibility of telehealth-administered assessment tools

Three of the six studies focussing on specific assessment tools evaluated the reliability of the Mini-Mental State Exam (MMSE) administered through telehealth videoconferencing compared to face-to-face. Ciemins et al. [40] tested 73 diabetes patients who were being screened for cognitive impairment. An in-person collaborator at the remote site was used to identify differences in recorded responses. Pearson correlation coefficients demonstrated high correlations ($\geq 86\%$) between 80% of items. McEachern et al. [41] studied 71 patients referred to a rural memory clinic in Canada and found no difference between in-person and telehealth MMSE scores. Loh et al. [42] assessed interrater reliability of two screening tests in 20 dementia patients in Australia. Correlations were higher for the MMSE (0.90) than for the Geriatric Depression Scale (GDS; 0.78). Remote GDS scores were higher than direct assessments.

Three studies in the US evaluated various test batteries. A study comparing a 5-test language battery administered via telehealth videoconferencing compared to in person in 15 memory clinic patients found no significant difference in performance [43]. A 5-question survey of participants indicated a high degree of acceptance with telehealth. Cullum et al. [44] administered a brief battery of neuropsychological tests via videoconferencing and face-to-face methods in 33 people with mild cognitive impairment or Alzheimer's Disease. Test scores were highly similar, and no participants expressed any concerns about telecognitive testing. Hogervorst et al. [45] administered three versions of a 10-item word recall list as part of a population-based telephone survey in Arkansas. Findings confirmed that the parallel versions were useful for telephone administration in research requiring repeated testing of episodic memory.

3.5.2 Dementia diagnosis, management, and consultation via telehealth

Five studies examined the use of telehealth to conduct a broader assessment of dementia aimed at diagnosis. Of these, three compared telehealth videoconferencing and traditional in-person clinical examinations in diagnosing dementia. In an Australian study [46], different geriatricians performed direct and remote assessments of 20 patients using five diagnostic tools. There were no significant differences between the two methods. In the US, Lott et al. [47] studied the feasibility of using telehealth to diagnose dementia in 90 individuals with Downs Syndrome. In both telehealth and in-person assessments the components of the neurologic, imaging, and neuropsychological examinations differentiated individuals with and without dementia. The third study comparing diagnostic reliability [48] evaluated 16 residents at admission to two Veterans' facilities. The telemedicine diagnoses were in 100% agreement with the diagnoses from the in-person clinical examinations. Study participants and medical personnel reported a high degree of satisfaction with telemedicine.

Morgan et al. [19] reported on the use of telehealth videoconferencing in a memory clinic in western Canada. Rural patients and family caregivers participated in a 30-minute pre-clinic telehealth assessment several weeks prior to a full-day interdisciplinary assessment in a tertiary care centre. Patients were randomly assigned to telehealth or in-person appointment for their first follow-up and then alternating at three time points in the first year. Results from the first 137 patients show high satisfaction with telehealth for pre-assessment and follow-up, particularly the reduced travel required. The average distance saved by telehealth was 428 kms. per round trip. The sixth study described a telepsychiatry consultation service provided from an academic medical centre to a rural skilled nursing facility in Australia [49]. Most of the weekly consultations concerned depression or dementia-related behavioural problems. Two years' experience demonstrated advantages over the previous monthly on-site visit, including more specialist time providing clinical service vs. travel, more frequent specialist presence, greater follow-through of recommendations, more family involvement, and reduced patient travel.

3.6 Long-term care

The long-term care theme (eight papers) includes three issues: end of life care, care worker stress, and the physical care environment.

3.6.1 End of life care

End of life care was the focus in two US-based studies. The first comparing the use of feeding tubes in US rural, midsize, and urban nursing homes found that rural nursing homes were less

likely to use feeding tubes than urban homes [50] and suggested that this may be due to fewer surgical specialists in rural areas; difficulties in recruiting highly trained nursing staff in rural nursing homes; and different attitudes towards end of life care in urban and rural areas that influenced care practices. The second investigated factors associated with the last 90 days of end-of-life medical services used by US nursing home residents with severe cognitive impairment [51] and found that rural nursing home residents experienced lower levels of medical care, in particular feeding tube use and intensive care unit admission, than urban nursing home residents. Rural nursing home residents had a higher risk of hospitalization than urban nursing home residents. They suggest this may be due to insufficient staffing of rural nursing homes, leading to increased hospitalization of residents.

Related to end of life care, an exploration of the pain management education needs of nurses (197 staff from 13 Australian facilities) caring for older people with dementia in rural aged care facilities found that many staff believed residents with dementia experienced pain and that “they could competently manage that pain” [38]. However they also found that in many aged care facilities staff did not have adequate knowledge to manage pain effectively, were generally unaware of pain management education opportunities, and had not attended in-house dementia training.

3.6.2 Care worker stress

Two Canadian studies examined the stress and strain of rural long-term care workers. The first evaluated the level of overall job strain among 110 nursing home staff working in seven rural nursing homes [52] and found that different staff groups reported different levels of strain. Nursing aides reported high job strain, activity workers reported active job strain, and registered nurses (RN) reported low job strain. Morgan et al. [52] suggested that job strain among nursing aides should be lowered by “improving opportunities for decision-making, creativity, and work variety”. They further suggest that different models of care (e.g. primary nursing, empowered aide) may improve dementia care delivery. The second compared work stress in nursing aides in eight rural nursing homes with SCUs and nursing aides in eight rural nursing homes without SCUs [39]. Nursing aides in homes with SCUs experienced benefits compared to nursing aides working in homes without SCUs, such as lower job strain and less exposure to aggression. Morgan et al. [39] concluded that SCUs may provide nursing aides with increased opportunity for learning, creativity, and work variety as well as more time to complete tasks.

3.6.3 Physical care environment

Three Canadian studies reported on the care environment in rural nursing homes. Morgan et al. [53] investigated the challenges associated with the social and physical environments of rural nursing homes. The seven rural nursing homes scored highest on the Physical Environment Assessment Protocol (PEAP) measures of provision of privacy, followed by facilitation of social contact, continuity of self, support of functional abilities, opportunities for personal control, quality of stimulation, maximize safety and security, regulation of stimulation, and maximize awareness and orientation. Physical environment problems were largely associated with the lack of SCUs, including problematic safety and noise levels, while nursing home staff reported problems related to both the physical environment and the social environment, including heavy workload and lack of dementia education.

Morgan et al. [54] described the development of SCUs in ten rural nursing homes. Nursing homes with SCU's offered improved dementia care due to their smaller size, homelike environments, and minimized stimulation. Empirical work comparing rural nursing homes with and without SCUs [55] found that facilities with SCUs scored more highly than integrated facilities indicating more supportive environments, leading to the conclusion that the smaller scale of rural nursing homes, in particular those with SCUs, compared to urban nursing homes may be a solid base for the provision of quality dementia care [39,53].

4. Discussion

4.1 Diagnostic processes

Recommendations from the reviewed studies focused on several strategies to improve dementia diagnosis and assessment in rural areas. Recommendations to improve capacity included offering dementia-specific continuing education opportunities [12], training that improves early recognition and diagnosis of dementia by rural GPs [15], as well as continuing education that accounts for limited access to specialists [11], and outreach strategies that account for challenges unique to rural primary care providers [13]. Researchers also called for improved access to local community-based services, including access to the Alzheimer's Association in rural areas [12,17]. Recommendations regarding alternative assessment services such as memory clinics were based on the need to provide dementia care in rural areas that overcomes limited resources [18] and the challenges of geography, primarily the time and cost to travel long distances to obtain health care [15,19,20]. The reviewed studies recommended further research that made comparisons among rural communities [16], investigated GPs' perceptions of geographical disadvantage [14], referral delays for diagnostic resources [14], GPs' dementia care practices [16], and the challenges faced by rural primary care providers of dementia care [13].

4.2 Service provision issues

Four main themes emerged in relation to service provision. Numerous barriers to accessing and using services were identified: the perception of rural people as self-sufficient and distrustful of outsiders [22,23,25], stigma of dementia [8,22,23], lack of awareness of services [8,23], lack of availability and choice in services [8,21,23], cost, travel, and lack of transport [8,25], and providing culturally sensitive care to diverse populations [23,25]. A second theme was the identification of case management and referral as strategies to address a number of these challenges. Two studies discussed the important role of rural GPs in early detection and subsequent referral [15,23]. Families depend on GPs because of the lack of other information sources in rural communities, thus it is critical that GPs have adequate training in recognizing dementia and awareness of available community support services. Nurses can play a significant role in ensuring services are matched to needs [24]. A third theme was the recommendation of increased collaboration, partnerships, and integration of services in rural communities. Finally, a number of studies identified issues of recruitment, retention, and training of formal care providers in rural communities. Local providers are more accessible than specialist services, but they may have had little training in dementia management [8,15,22,23].

4.3 Service models and programs

Reflecting the identified issues in rural service delivery described above, including lack of awareness of services and limited self-referral, most of the programs reported in the literature focused on case management and referral. Common components included in-home assessment of

patient and caregiver needs, care management, service provision and/or referral, and caregiver and public education [28-31]. Coordination, collaboration, and integration of existing formal services and informal supports were recommended as key strategies for addressing the shortage of services, resources, and fragmented care systems.

4.4 Staff education and support needs

The possibility for education as a way to improve rural dementia care was mentioned frequently in the literature. Pain management education in long-term care was suggested [38] while dementia care training for rural nursing home staff was seen to be important in reducing job stress and improving job satisfaction [52]. As with non-rural nursing homes, job strain among nursing aides may be reduced by addressing staff shortages, increasing staff levels, including improving the staff-to-resident ratio, as well as increasing nursing aides' decision authority and skill discretion [52].

4.5 Use of technology

The limited research to date indicates that the MMSE [40-42] and several other neuropsychological tests [43-45] can be administered reliably through telehealth videoconferencing, and that patient acceptance is high. Two small studies [46,47] and one larger study [48] reported accurate diagnosis of dementia via telehealth. Telehealth has been shown to be effective for pre-assessment and follow-up in conjunction with an in-person interdisciplinary memory clinic assessment [19], and for distance consultation for rural nursing home patients [49]. The included studies recommended more research on the validity and reliability of telehealth compared to in-person care, and to evaluate patient and provider satisfaction.

4.6 Long-term care

The demand for specialized dementia care environments in rural nursing homes may increase due to the desire of rural seniors to stay in their communities, alongside the global aging population. As Morgan et al. [53] argued, the physical environment might be improved without developing SCUs by decreasing non-meaningful stimulation and increasing quality stimulation, providing more environmental clues, developing dementia-specific programs, providing more education opportunities for staff, and attending to staff workload issues. The smaller scale of rural nursing homes, compared to urban nursing homes, and the personal relationships between staff and residents, may be a solid base for the provision of quality dementia care [53]. The absence of specialist end of life care [50,51] suggests more attention needs to be placed on this aspect of long-term care, as does pain management [38]. It has also been argued that more research is required about rural residents' life experiences and whether they have a greater acceptance of death, and on rural practices to improve end of life care [50,51]. They also suggest that rural-urban end of life care differences should be explored.

5. Conclusion

The studies included in this review of formal caregiving span the care continuum, from early detection and diagnosis, to availability and access to a range of community-based services and education programs, to appropriate long-term care settings and services. Missing was research related to non-institutional housing options as an option between home and long-term care. Three recurring issues are capacity development and training, use of technology, and care coordination and management. There is a need for more basic and continuing dementia-specific training of

formal caregivers who provide services in rural communities, including family physicians, nurses and other allied health professionals, and home-care and nursing home staff. Given the limited number and types of services available in sparsely populated rural areas it may not be possible to provide a full range of separate specialized services for those with dementia. Thus developing the capacity of rural providers is critical to ensuring their comfort and competency in delivering high quality care across the different types of service provision. Formal caregivers play a key role in supporting patients and family caregivers and must have the necessary skills to fulfill this role. As this review has identified, technology such as telehealth is being used for staff development and service delivery. More research is needed to understand the potential of technology for these purposes.

Another area of agreement in this body of research is the need for integrated and coordinated care across the continuum from early diagnosis to end of life care. The concept of case management emerged as a strategy to ensure that available services are used. Such programs depend on formal providers being aware of community resources and understanding the impact of dementia on patients and family caregivers over time. Public awareness, early diagnosis, and referral are essential components of such programs, as is the availability of adequate services within the community. Most models of specialist care have typically involved either rural patients traveling to urban centres, specialists traveling to rural areas (outreach services), or more recently, use of technology such as telehealth to bridge geographic barriers. While outreach programs and technology help to reduce travel burden for episodic specialist care, the challenge remains to provide appropriate support and services in the rural community across all stages of the dementia trajectory.

Over the last 20 years, the period covered by this review, the number and scope of studies exploring aspects of care for individuals with dementia in rural and remote areas has grown, but the evidence for policy and program planning remains limited. Although 46 studies were found that examined formal care, these are distributed across a broad spectrum of care. Most of the existing studies have been small descriptive studies. The research is limited to a small number of countries and we found no comparative studies across countries or application of learning from one country to another. These findings are a concern given that a significant proportion of older people worldwide live in rural settings and that the prevalence of dementia is increasing due to population aging. The review identified examples of successful programs and services targeted to various stages of the care continuum (e.g., memory clinics, information and referral services, consultation to long-term care facilities). These studies contribute to the body of evidence needed to support policy and program development, but strategies are needed to link these various elements into comprehensive and coordinated models of rural dementia service delivery. Given the great variability in types of rural settings globally, it is clear that one size will not fit all, thus the need for a range of rural dementia care models that can be adapted to local needs.

References

- [1] Alzheimer Disease International. World Alzheimer Report 2009. Available from: <http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf>.
- [2] Wimo A, Winblad B, Jonsson L. An estimate of the total worldwide societal costs of dementia in 2005. *Alzheimer's and Dementia* 2007;3:81-91.
- [3] Knapp M. Dementia: A new global epidemic? *Maturitas* (2010), doi:10.1016/j.maturitas.2010.06.015
- [4] Dandy K, Bollman R. Seniors in rural Canada. *Rural and Small Town Canada Analysis Bulletin* 2008;7(8):1-56. Statistics Canada, Cat no. 21-006-X.
- [5] Huber M, Stanciole A, Bremmer J, Wahlbeck, K. Quality in and equality of access to healthcare & services. European Commission, Directorate-General for Employment, Society Affairs and Equal Opportunities; 2008.
- [6] National Advisory Committee on Rural Health & Human Services. The 2008 report to the Secretary: Rural Health and Human Service Issues. Available from: <ftp://ftp.hrsa.gov/ruralhealth/committee/NACreport2008.pdf>.
- [7] Keefover R, Rankin E, Keyl P, Wells J, Martin J, Shaw J. Dementing illnesses in rural populations: The need for research and challenges confronting investigators. *J Rural Health* 1996;12(3):178-87.
- [8] Innes A, Cox S, Smith A, Mason A. Service provision for people with dementia in rural Scotland: Difficulties and innovations. *Dementia* 2006;5(2):249-70.
- [9] Baldwin C, Mackenzie J. Service needs and delivery following dementia diagnosis: Evidence based review. Bradford Dementia Group, School of Health Studies, Univ of Bradford. Retrieved Nov 2009: <http://www.ruralcommunities.gov.uk/files/Dementia%20report%20formatted.pdf>.
- [10] Mueller, K, MacKinney, A.C. Care across the continuum: Access to health care services in rural America. *National Rural Health Assoc* 2006; 22(1): 43-9.
- [11] Alexander C, Fraser J. General practitioners' management of patients with mental health conditions: The views of general practitioners working in rural north-western New South Wales. *Aust J Rural Health* 2008;16(6):363-9.
- [12] Meuser TM, Boise L, Morris JC. Clinician beliefs and practices in dementia care: Implications for health educators. *Educ Gerontol* 2004;30(6):491-516.
- [13] Teel CS. Rural practitioners' experiences in dementia diagnosis and treatment. *Aging Ment Health* 2004;8(5):422-9.
- [14] Cahill S, Clark M, O'Connell H, Lawlor B, Coen RF, Walsh C. The attitudes and practices of general practitioners regarding dementia diagnosis in Ireland. *Int J Geriatr Psych* 2008;23(7):663-9.
- [15] Gilmour H, Gibson F, Campbell J. People with dementia in a rural community: Issues of prevalence and community care policy. *Dementia* 2003;2(2):245-63.
- [16] Camicioli R, Willert P, Lear J, Grossmann S, Kaye J, Butterfield P. Dementia in rural primary care practices in Lake County, Oregon. *J Geriatr Psych Neur* 2000;13(2):87-92.
- [17] Hansen EC, Hughes C, Routley G, Robinson AL. General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Soc Sci Med* 2008;67(11):1776-83.
- [18] Cheung G, Strachan J. A survey of memory clinics in New Zealand. *Australas Psychiatry* 2008;16(4):244-7.

- [19] Morgan DG, Crossley M, Kirk A, D'Arcy C, Stewart N, Biem et al. Improving access to dementia care: development and evaluation of a rural and remote memory clinic. *Aging Ment Health* 2009;13(1):17-30.
- [20] Crossley M, Morgan D, Lanting S, Dal Bello-Haas V, Kirk A. Interdisciplinary research and interprofessional collaborative care in a memory clinic for rural and northern residents of western Canada: Unique training ground for clinical psychology graduate students. *Aust Psychol* 2008;43(4):231-8.
- [21] Shope JT, Holmes SB, Sharpe PA, Goodman C, Izenson S, Gilman S, et al. Services for persons with dementia and their families: A survey of information and referral agencies in Michigan. *Gerontologist* 1993;33(4):529-33.
- [22] Glueckauf RL, Stine C, Young ME, Massey A, Ashley P. Alzheimer's rural care healthline: Linking rural caregivers to cognitive-behavioral intervention for depression. *Rehabil Psychol* 2005;50(4):346-54.
- [23] Karner TX, Hall LC. Successful strategies for serving diverse populations. *Home Health Care Serv Q* 2002;21(3-4):107-31.
- [24] Mason A, Blackstock K, Cox S, Innes A, Smith A. Dementia services in rural areas: Nursing implications. *Nurs Older People* 2005;17(9):20-3.
- [25] McDonald A, Heath B. Developing services for people with dementia. *Quality in Ageing* 2008;9(4):9-18.
- [26] Buckwalter K. Interventions for family caregivers of patients with Alzheimer's disease in community-based settings: Items for consideration. *Int Psychogeriatr* 1996;8(Suppl 1):121-2.
- [27] Fox GK, Withaar F, Bashford GM. Dementia and driving: A survey of clinical practice in aged care assessment teams. *Aust J Ageing* 1996;15(3):111-4.
- [28] Schraeder C, Shelton P, Dworak D, Fraser C. Alzheimer's disease: case management in a rural setting. *J Case Manag* 1993;2(1):26-31.
- [29] Turyn RM. Developing programs to meet the needs of Alzheimer's families in rural Maine. *J Appl Gerontol* 2001;20(2):241-50.
- [30] Kelly CM, Williams IC. Providing dementia-specific services to family caregivers: North Carolina's project CARE program. *J Appl Gerontol* 2007;26(4):399-412.
- [31] Vissing YM, Salloway JC, Siress DL. Organization of Alzheimer's services for rural areas. *Educ Gerontol* 1994;20(3):303-18.
- [32] Coogle CL. The families who care project: Meeting the educational needs of African American and rural family caregivers dealing with dementia. *Educ Gerontol* 2002;28(1):59-71
- [33] Connell CM, Holmes SB, Voelkl JE, Bakalar HR. Providing dementia outreach education to rural communities: Lessons learned from a train-the-trainer program. *J Appl Gerontol* 2002;21(3):294-313.
- [34] Rankin ED, Keefover RW, Nichols AH. Training rural health care and social service providers in assessment and care of dementia. *Gerontol Geriatr Educ* 1997;17(2):33-48.
- [35] Goins RT, Gainor SJ, Pollard C, Spencer SM. Geriatric knowledge and educational needs among rural health care professionals. *Educ Gerontol* 2003;29(3):261-72.
- [36] Bellaver C, Daly JM, Buckwalter KC. Information resources and knowledge needs of rural nurses regarding Alzheimer's disease. *J Contin Educ Nurs* 1999;30(3):114-9.
- [37] Paul L, Johnson AO, Cranston GM. A successful videoconference satellite program: Providing nutritional information on dementia to rural caregivers. *Educ Gerontol* 2000;26(5):415-25.

- [38] Neville C, McCarthy A, Laurent K. Pain management skills of regional nurses caring for older people with dementia: A needs analysis. *Collegian* 2006;13(2):31-6.
- [39] Morgan DG, Stewart NJ, D'Arcy C, Forbes D, Lawson J. Work stress and physical assault of nursing aides in rural nursing homes with and without dementia special care units. *J Psychiatric Ment Hlt* 2005;12(3):347-58.
- [40] Ciemins EL, Holloway B, Coon PJ, McClosky-Armstrong T, Min SJ. Telemedicine and the Mini-Mental State Examination: Assessment from a Distance. *Telemed J E-Health* 2009;15(5):476-8.
- [41] McEachern W, Kirk A, Morgan DG, Crossley M, Henry C. Reliability of the MMSE administered in-person and by telehealth. *Can J Neurol Sci* 2008;35(5):643-6.
- [42] Loh PK, Donaldson M, Flicker L, Maher S, Goldswain P. Development of a telemedicine protocol for the diagnosis of Alzheimer's disease. *J Telemed Telecare* 2007;13(2):90-4.
- [43] Vestal L, Smith-Olinde L, Hicks G, Hutton T, Hart J Jr. Efficacy of language assessment in Alzheimer's disease: Comparing in-person examination and telemedicine. *Clin Interv Aging* 2006;1(4):467-71.
- [44] Cullum CM, Weiner MF, Gehrman HR, Hynan LS. Feasibility of telecognitive assessment in dementia. *Assessment* 2006;13(4):385-90.
- [45] Hogervorst E, Bandelow S, Hart J, Henderson VW. Telephone word-list recall tested in the Rural Aging and Memory Study: Two parallel versions for the TICS-M. *Int J Geriatr Psych* 2004;19(9):875-80.
- [46] Loh PK, Ramesh P, Maher S, Saligari J, Flicker L, Goldswain P. Can patients with dementia be assessed at a distance? The use of Telehealth and standardised assessments. *Intern Med J* 2004;34(5):239-42.
- [47] Lott IT, Doran E, Walsh DM, Hill MA. Telemedicine, dementia and Down syndrome: Implications for Alzheimer disease. *Alzheimers Dement* 2006;2(3):179-84.
- [48] Shores MM, Ryan-Dykes P, Williams RM, Mamerto B, Sadak T, Pascualy M, et al. Identifying undiagnosed dementia in residential care veterans: Comparing telemedicine to in-person clinical examination. *Int J Geriatr Psychiatry* 2004;19(2):101-8.
- [49] Johnston D, Jones BN. Telepsychiatry consultations to a rural nursing facility: A 2-year experience. *J Geriatr Psych Neur* 2001;14(2):72-5.
- [50] Gessert CE, Calkins DR. Rural-urban differences in end-of-life care: The use of feeding tubes. *J Rural Health* 2001;17(1):16-24.
- [51] Gessert CE, Haller IV, Kane RL, Degenholtz H. Rural-urban differences in medical care for nursing home residents with severe dementia at the end of life. *J Am Geriatr Soc* 2006;54(8):1199-1205.
- [52] Morgan DG, Semchuk KM, Stewart NJ, D'Arcy C. Job strain among staff of rural nursing homes: A comparison of nurses, aides, and activity workers. *J Nurs Admin* 2002;32(3):152-61.
- [53] Morgan DG, Semchuk KM, Stewart NJ, D'Arcy C. The physical and social environments of small rural nursing homes: Assessing supportiveness for residents with dementia. *Can J Aging* 2003;22(3):283-96.
- [54] Morgan DG, Stewart NJ, D'Arcy C, Cammer AL. Creating and sustaining dementia special care units in rural nursing homes: The critical role of nursing leadership. *Can J Nurs Leadership* 2005;18(2):74-99.
- [55] Morgan DG, Stewart NJ, D'Arcy KC, Werezak LJ. Evaluating rural nursing home environments: Dementia special care units versus integrated facilities. *Aging Ment Health* 2004;8(3):256-65.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Diagnostic processes			
Alexander and Fraser 2008 New South Wales	Survey (38 rural GPs) Investigate physicians' barriers to management and support needs regarding patients with mental health disorders	not provided	- Rural GPs were most confident and referred patients with depression, anxiety and dementia in that ranked order.
Cahill et al. 2008 Ireland	Survey (300 rural and urban GPs) and focus group (7 rural GPs) Describe GP beliefs about late dementia diagnosis, barriers to diagnosis, service and training needs, and access to diagnostic and specialist resources	1996 Census definition of urban and rural	- time delays in secondary service access did not differ by urban-rural location but rural GPs believed geographical location results in poor access to CT scans and MRIs.
Camicoli et al. 2000 United States	Chart review (51 patients from four rural family physician practices and one nursing home, aged >65 years, with an ICD-9 code relevant to a dementia diagnosis) Determine the prevalence of documented dementia in rural clinical practice, and investigate whether family physicians follow current recommendations in dementia assessment	One town with a population of 2,880, in the largely rural state of Oregon.	- family physicians recorded "memory impairment, functional decline, and a history of progression", but only rarely conducted mental status tests. - "physician judgement was insensitive to the diagnosis of mild dementia".
Cheung and Strachan 2008 New Zealand	Survey (21 District Health Boards, 8 with a memory clinic) Investigate the funding structure and staffing level of 8 publicly funded memory clinics in New Zealand	not provided	- Some parts of the country had easier access to a memory clinic than other parts, resulting in inequality of access to dementia diagnosis and management. - neurologists did not provide input to any of the eight memory clinics. - three of the eight clinics had no dedicated funding
Crossley et al. 2008 Canada	Program evaluation Academic program and memory clinic Describe a Graduate Program in Clinical Psychology and "the role of clinical neuropsychology in an innovative interprofessional rural and remote memory clinic"	Rural: "> 100 km from major tertiary care centres".	- dementia management is challenging for rural residents due to a lack of service options and distance from urban care centres, - indigenous people in rural, remote and northern regions require culturally appropriate dementia assessment and care, although their particular needs have not been adequately identified. - "RRMC is achieving many of its treatment goals for increased access and convenience for rural residents" - a one-day memory clinic that employs telehealth for pre-clinic and follow-up assessment is a useful way to deliver dementia services.
Gilmour et al. 2003 Ireland	Survey (435 rural people with dementia) Examine the prevalence of dementia and health and social conditions of people with dementia	rural county in Northern Ireland	- the higher prevalence of dementia among GP patients older than 75 years indicates that GPs may be recognizing people with dementia during patients' annual over-75 check-ups. - a greater proportion of people with dementia in the main study town than in the rural area resided in long-term care.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Hansen et al. 2008 Australia	One focus group (5 GPs), two focus groups (7 GPs), and semi-structured interviews (13 GPs), including rural, large town, and urban GPs Explore GPs' views about dementia diagnosis	not provided	- rural GPs were more likely to diagnose patients with dementia. Urban GPs were more likely to refer patients to specialists - rural GPs were reluctant to refer to psycho-geriatricians due to "a more autonomous approach to their practice", lack of access, patient travel
Meuser et al. 2004 United States	Survey (Clinicians in the US state of Missouri, including 422 primary care physicians, 144 specialists, 185 advanced practice nurses, and 40 physician assistants) Compare knowledge, confidence, attitudes, and practice among clinicians, and examine continuing education preferences	Rural was defined as farming communities or small towns. Respondents who classified 0%-10% of their elder practice as rural were considered 'mainly urban', 20%-60% as 'mixed', and 70%-100% as 'mainly rural'.	- urban and rural clinicians did not differ in their knowledge, care confidence, attitudes, care practices, and motivation for learning. - compared to urban clinicians, rural clinicians were more interested in dementia-specific continuing education programs, more likely to prefer programs delivered by lecture or a hands-on workshop, and more likely to indicate that the Alzheimer's Association "did not provide accessible education and support services for dementia patients and their families".
Morgan et al. 2009 Canada	Service evaluation (137 rural or remote persons with possible dementia aged ≥ 42 years) Describe development, operation, and evaluation of an interdisciplinary memory clinic to diagnose and manage rural and remote persons with possible dementia	Rural was defined as "populations living more than 100 km (62 miles) from two major cities". Remote was defined as "communities within the three northern" regional health authorities.	- challenges of operating a memory clinic for rural and remote residents include the inability to meet demand; travel barriers - successes include patient and family satisfaction with a one-day assessment clinic that provides an immediate diagnosis, as well as satisfaction with telehealth; team assessment that includes family caregiver(s); transdisciplinary assessment that improves students' exposure to interprofessional care from many different disciplines.
Teel 2004 United States	Semi-structured interview (19 primary care providers in one midwestern US state) Describe experiences of primary care providers in rural areas regarding diagnosis and treatment of people with dementia	communities with <25,000 persons.	- all rural providers had access to lab and imaging equipment necessary. - rural providers valued specialist services for diagnosis and treatment planning even if access was limited - the family plays an important role in early diagnosis, but sometimes do not seek help early due to a lack of knowledge; family can facilitate or hinder patient care; there is a lack of education and support opportunities - rural providers did not refer to lack of time as a factor in diagnosis, were skeptical about effectiveness of current treatment, were aware of stigma and used terms other than dementia - most primary care providers administered the MMSE and indicated that it had more value as a screening rather than diagnostic tool.
Service provision			
Gilmour et al. 2003 Ireland	see Diagnostic Processes theme above		

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Glueckauf et al. 2005 United States	One focus group (12 rural health care providers), one focus group (12 African American pastors, church elders, community leaders, and caregivers), and one focus group (9 non-Hispanic White pastors, church elders, community leaders, and caregivers) in the US state of Florida Investigate the education and support needs of rural caregivers of people with dementia	rural county of the Florida panhandle	- health care providers, pastors, church elders, community leaders, and caregivers indicated that rural caregivers require education about diagnosis and treatment of Alzheimer’s disease and need information about community support services available.
Innes et al. 2006 Scotland	Survey and semi-structured interviews (86 rural and remote dementia service providers) Investigate barriers to dementia service provision to rural people with dementia and their caregivers, and innovative dementia service provision	Three categories of rural and remote, based on Scottish Household Survey (Scottish Executive).	- rural and remote dementia service providers reported barriers to providing dementia services: “distance and lack of transport, the cost of the service for the user, a lack of choices in services, and a shortage of skilled staff”. - rural and remote service providers described innovative methods to improve dementia service provision (transportation, outreach, joint working) but these were threatened by time and resources limitations.
Karner and Hall 2002 United States	Open-ended interview (42 frontline staff and 8 administrators) Investigate perceptions of frontline staff providing services to people with dementia and their caregivers	not provided	- rural communities had few opportunities for health and education services, and a unique culture based on social isolation and self-sufficiency. - churches were extensions of rural residents’ families - residents were somewhat homogeneous and distrusted outside providers. - Alzheimer’s diseases was stigmatized as a mental illness or seen as normal aging in rural communities - family caregivers felt guilt, anxiety, and stigma in using respite care, however younger caregivers were less reluctant about using such services. - family caregivers preferred service providers who were familiar and of similar ethnicity, until they gained trust in the service providers. - due to low pay, staff retention was difficult in rural areas. - barriers to service provision included transportation, funding, staffing, lack of physician understanding and referral, patients’ fear of bureaucracy. - providers addressed barriers with creative solutions that met client needs, such as defining respite care as complementary to family care, developing transportation support, telephone support groups, and newsletters. - effective rural respite programs incorporated trust, support, consistency.
Mason et al. 2005 Scotland	Survey (86 service providers to rural and remote people with dementia and their caregivers) Investigate availability, accessibility and costs of service provision to rural people with dementia and their caregivers	not provided	- nurses and self-referral were the main access points for service. - identified service gaps included: services for people living at home(39%), service choices (30%), specialist services (27%), long-stay care (26%), shortage of skilled staff (23%), specialist training and recruitment/retention of suitable staff (10%), transportation for services users (5%). - joint working practices that improved service access included “consultation, assessment, planning, commissioning, and funding”.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
McDonald and Heath 2008 United Kingdom	Interviews (Dementia care group with members from 'statutory, voluntary, and community sectors') Examine service provision to people with dementia and their caregivers in 3 rural counties in East Anglia	not provided	<ul style="list-style-type: none"> - dementia care providers indicated that "service strategy documents" were prompting changes in areas including keeping older people at home, increasing person-centred care and carer support, agency partnership and specialist skill sharing, and "adapting service development". - service provision was "patchy as it had grown up in response to very local need in rural communities". - independent sector lacked training opportunities, had recruitment issues. - difficulties included balancing regional and local needs, and providing integrated or separate dementia services. Rural culture impeded change. - areas of unmet need included service provision to people with early onset dementia, as well as to persons with learning difficulties. - the shortfalls of the statutory sector in dementia care provision have been filled by the community and voluntary sectors.
Shope et al. 1993 United States	Survey (91 urban and 128 non-urban agencies that provided information and referral services to people with dementia and their families) in the US state of Michigan Explore service availability, families' needs, and problems in providing information and referral to people with dementia and their families	Rural was defined as non-urbanized, and an urbanized area was defined as "comprising one or more places and the adjacent densely settled surrounding territory that together have a minimum of 50,000 persons."	<ul style="list-style-type: none"> - urban agencies "were significantly more likely to report a physician specializing in elder care within 50 miles". - non-urban agencies were significantly more likely than urban agencies to report client inaccessibility to services that included assessment and diagnosis, support, counseling, education/information, legal services, adult day care, and respite care. - non-urban agencies were significantly more likely than urban agencies to mention an unmet need for adult day care and respite care
Service models and programs			
Buckwalter 1996 United States	Position paper Call for improved services for people with dementia and their caregivers in rural settings	not provided	
Fox et al. 1996 New South Wales	Survey (38 Aged Care Assessment Teams [ACATs], including 19 rural and 19 urban) Investigate how ACATs assess fitness to drive in people with dementia	not provided	<ul style="list-style-type: none"> - In rural and urban settings, fewer than half of the ACATs indicated that they used driving evaluations to assess fitness to drive. - remote rural ACATs were more likely to prescribe restricted license vs. assessing clients as unfit to drive, due to unavailability of public transit. - rural ACATs were less likely to perform repeated assessments, perhaps due to long travel distances for patients and lack of ACATs resources.
Kelly and Williams 2007 United States	Case study by semi-structured interview (3 family consultants who coordinate support services for rural and minority families of dementia patients in the US state of North Carolina) Describe family consultants' perceptions of Project CARE (Caregiver Alternatives to Running on Empty)	not provided	<ul style="list-style-type: none"> - family consultants vary in the resources that they employ to implement their programs, eg public resources vs. religious community - family consultants built community partnerships to connect caregivers with existing respite services. - the family consultants integrated the Project CARE programs into existing Alzheimer's Associations, and public health and social services programs.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Schraeder et al. 1993 United States	Health service evaluation (Approximately 400 persons with Alzheimer's disease and their caregivers) Describe the Carle case management model to deliver health and social services to persons with Alzheimer's and their family caregivers in rural communities in the US states of Illinois and Indiana	not provided	<ul style="list-style-type: none"> - the Carle case management model facilitated service coordination and communication, combined formal and informal systems of support, and allowed "for client advocacy and system development" and encouraged communication between service providers, caregivers, and clients - the Carle case management model included assessment of informal services used by rural clients and caregivers, which allowed case managers to intervene in cases where independent living arrangements needed to be maintained, and to integrate formal with informal services. - the Carle case managers acted as advocates for clients to access appropriate services and to close service gaps.
Turyn 2001 United States	Service development and evaluation Describe three programs that were developed for persons with Alzheimer's disease and their families in the US state of Maine	rural was defined as "93% of the communities have populations of fewer than 2,000 people".	<p>Three services were developed: (1) respite programme that provided caregivers with \$3500 of annual respite care of their choice, (2) the Geriatric Dementia Evaluation Program included six teams of health care professionals (nurse, social worker, and geriatrician) that provided in-home evaluations of rural persons with possible dementia, assessment of caregiver depression, service referrals, and information and education. (3) the Rural Alzheimer's Physician Education Project was developed to educate rural physicians about diagnosing Alzheimer's disease and increase their awareness about resources for families.</p>
Vissing et al. 1994 United States	Health service evaluation Describe the development and evaluation of three program models to deliver services to Alzheimer's patients in rural areas in the US state of New Hampshire	not provided	<ul style="list-style-type: none"> - the Imported Model (IM) (service providers come in to the area) has disadvantages that include service providers being unfamiliar with the rural community and being considered 'outsiders'. - the Local Initiative Model (LIM)(local resources are organized to offer services) advantages include service provider familiarity with local residents and other health care providers, and low start-up costs. The disadvantage is providing services based on little or no training. - evaluation of the Partnership model (combines IM and LIM) showed that family caregivers were highly satisfied, that their quality of life had improved, and that those with Alzheimer's disease remained in their homes. Disadvantages included the complexity of its administration, and problems associated with combining imported and local resources.
Staff education and support needs			
Bellaver et al. 1999 United States	Survey (53 RNs and LPNs working in long-term care or home health care in rural settings in the US state of Iowa) Assess nurses' continuing education and telephone consultation needs	Rural: population base of ≤ 25,000.	<ul style="list-style-type: none"> - nurses reported most interest in the educational topics of challenging behaviors, family needs, case management, long term care services, and new developments in AD. - nurses reported that they would access a telephone consultation service for family and community care, behavior management, and diagnosis.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Connell et al. 2002 United States	Education intervention study (27 rural health care providers (Trainers) and 3276 rural Learners) Describe an information dissemination program about dementia, targeted to healthcare professionals in rural Michigan.	Three categories of counties: rural, low density urban, high-density urban (adapted from rural-urban continuum codes defined by Economic Research Services, U.S. Dept of Agriculture).	- knowledge about dementia increased among learners and trainers after attending the Dementia Education Train-the-Trainer Program (DE-TTT-P). - telephone conference calls, intended to connect trainers with one another, were rated as “very effective” by half of the trainers. - Trainers who were healthcare professionals were more effective than trainers who were administrators at “sustaining their educational efforts in the community” because they incorporated training into their paid work
Crossley et al. 2008	see Diagnostic Processes theme above		
Coogle 2002 United States	Education intervention study (39 members of community advisory groups, and 106 African American and rural family caregivers) Describe a Train-the-Trainer program of family caregivers in Virginia	not provided	- it is essential that Trainers include “culturally or racially compatible professional staff” in outreach projects. - using “trusted community leaders” as trainers of caregivers has lasting implications, since these leaders typically stay in their communities and become “known experts” on dementia.
Gilmour et al. 2003	see Diagnostic Processes theme above		
Glueckauf et al. 2005	see Service Provision theme above		
Goins et al. 2003 United States	Survey (84 rural health care providers in the US state of West Virginia) Identify the knowledge, educational needs, and continuing educational preferences of rural health care providers, about geriatrics	Rural: 43 non-metropolitan counties in West Virginia’s	- geriatric knowledge was rated as average by about half of the rural health care providers, and the majority wanted to learn more about geriatrics. - rural health care providers wanted to learn more about the geriatric topics of “Alzheimer’s disease/dementia, medication use/polypharmacy, and adverse medication events” and preferred local vs. distance learning.
Innes et al. 2006	see Service Provision theme above		
Karner and Hall 2002	see Service Provision theme above		
McDonald and Heath 2008	see Service Provision theme above		
Meuser et al. 2004	see Diagnostic services theme above		

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Morgan et al. 2005 Canada	Survey (355 nursing aides from eight rural nursing homes with special care units [SCUs] and eight rural nursing homes without [SCUs] Compare nursing aides in rural nursing homes with SCUs and nursing aides in rural nursing homes without SCUs on measures of work stress and disruptive and aggressive behavior	Rural centres had a population of 15,000 or less.	<ul style="list-style-type: none"> - nursing aides (NAs) working in rural nursing homes with SCUs experienced less stress than NAs in rural nursing homes without SCUs. - NAs who worked in rural nursing homes with SCUs, not just those who worked particularly in the SCUs, experienced benefits. - NAs in rural non-SCU facilities had a greater risk of physical assault - one-third of NAs working in rural nursing homes with SCUs and one-half of NAs working in rural non-SCU nursing homes had not attended dementia specific continuing education programs. Barriers included cost, lack of programs, and the requirement to attend on their own time. - improved staff levels may reduce physical assault, as staff have more time to spend with residents and do not need to rush care.
Neville et al. 2006 Australia	Survey (197 staff from 13 aged care facilities, including 55 RNs, 19 enrolled nurses, and 120 unlicensed nurses) Explore pain management education needs of nurses caring for older people with dementia in rural aged care facilities	not provided	<ul style="list-style-type: none"> - many aged care facilities staff believed that their residents with dementia experienced pain and that “they could competently manage that pain” but did not have adequate knowledge to manage pain effectively. - staff were generally unaware of pain management education programs and local interest groups, and did not attending in-service on pain management -continuing education preferences of aged care facilities staff included face-to-face training, and continued support after program completion. - barriers to continuing education included cost, lack of information, travel distance, and difficulty covering staff attending programs.
Paul et al. 2000 United States	Education intervention (66 rural caregivers in the US state of Montana) Assess distance education for rural professional and family caregivers of people with dementia about nutrition and dementia, and provide a forum for interaction between professional and family caregivers	not provided	<ul style="list-style-type: none"> - the majority of rural caregiver attendees rated the videoconference as good or better, found the content to be relevant to work/home, had previously attended a videoconference, and intended to attend another. - strengths of the videoconference cited by attendees included the information provided by the speakers and in handouts, time and travel saved, interaction with other attendees, immediate answers to questions. - attendees suggested including a social worker on the videoconference panel to answer questions about community resources, and to provide more practical information on “direct food-related caregiving tasks”.
Rankin et al. 1997 United States	Education intervention (125 rural health care and social service providers from 27 counties in the US state of West Virginia) Train rural health care and social services providers to detect cognitive disorders and offer management options, using Training Rural Alzheimer’s Networking Services for Education and Referral (Transfer) program workshops	not provided	<ul style="list-style-type: none"> - rural health care and social service providers’ dementia knowledge significantly improved after participating in the Transfer program. - health care providers learned more than social service providers - the attitudes of providers toward elders did not significantly vary after participating in the program, however lower attitudinal ratings were associated with increased use of community resource directories. - most health care providers continued to use patient-related materials from the Transfer program 6 or more months after participating in the program.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Teel 2004	see Diagnostic Processes theme above		
Turyl 2001	see Service Models and Programs theme above		
Vissing et al. 1994	see Service Models and Programs theme above		
Use of Technology			
Ciemins et al. 2009 United States	Instrument validation study (73 diabetes self-management study participants) Compare reliability of MMSE administered by telehealth and in-person	not provided	<ul style="list-style-type: none"> - in-person and telehealth MMSE scores were highly correlated, with no significant mean differences in scores. - potential errors in MMSE testing would likely be false positives. - cognitive testing by MMSE with telehealth has utility for lower functioning patients, since such testing is not likely to miss cognitive impairment in lower functioning patients.
Cullum et al. 2006 United States	Instrument validation study (14 people with MCI, and 19 people with mild to moderate AD) Pilot study to compare telecognitive and in-person neurocognitive assessments	not provided	<ul style="list-style-type: none"> - telecognitive and in-person cognitive test scores were positively associated. - participants were able to adapt to the video-conferencing technology, and likely do not require a caregiver with them during testing. - sound and picture quality of the video-conferencing technology were not a barrier to use.
Hogervorst et al. 2004 United States	Survey (1845 household residents aged 40 to 95 years in the US state of Arkansas) Compare three versions of 10-item telephone-administered word list recall tasks used to assess memory in persons aged 40 to 95 years	One U.S. county with the following characteristics: 'no designated urban areas' of $\geq 10,000$ and 45% of persons lived in rural areas of $< 2,500$.	<ul style="list-style-type: none"> - the performance outcomes were similar on each of the three versions of the 10-item word list recall tasks. - when the results of all three word lists were combined, in the middle-aged group, women performed better than men and those with more education performed better than those with less education.
Johnston and Jones 2001 Australia	Health service evaluation (40 telepsychiatry consultation patients aged 60 to 95 years) Evaluate a telepsychiatry program in an academic medical centre provided to geriatric patients in a rural skilled nursing facility	town with a population of 5,000	<ul style="list-style-type: none"> - compared with once-monthly in-person visits by a psychiatrist, telepsychiatry increased the number of patient consultations. - weekly telepsychiatry visits allowed the psychiatrist to have on-going contact with patients and staff. - nurse involvement during the telepsychiatry session increased the likelihood of accountability and 'follow-through of recommendations'. - patients appreciated the travel saved by the telepsychiatry service, and families appreciated the opportunity to attend the sessions.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Loh et al. 2004 Australia	Instrument validation study (20 persons with possible dementia aged ≥ 72 years chosen from a “postoperative rehabilitation unit for the fractured-neck-of-femur unit” and “an acute aged care medical unit”) Compare interrater reliability of SMMSE and GDS via telehealth and in-person AD assessments	not provided	- the mean difference between telehealth and in-person assessment was moderate (0.3+2.2 for the SMMSE scores, and 0.3+2.1 for the GDS scores . - audio difficulties emerged when using lower bandwidth during telehealth assessments.
Loh et al. 2007 Australia	Instrument validation study (20 persons with possible dementia aged ≥ 67 years, referred by GPs) Compare validity of telemedicine and in-person AD assessments	not provided	- good agreement between in-person and telemedicine assessments. - the in-person assessment scores indicated less cognitive impairment overall, with 0.36 difference in mean scores between telemedicine and in-person assessments. - in-person Informant Questionnaire for Cognitive Decline in the Elderly (IQCODE) scores of carers were higher than telemedicine IQCODE scores.
Lott et al. 2006 United States	Cognitive assessment (90 persons with Down Syndrome in the US state of California) Compare the process of diagnosing Dementia of the Alzheimer type (DAT) by telemedicine and in-person in persons with Down Syndrome living in remote settings, as well as the feasibility of telemedicine DAT assessment for this patient population	not provided	- there were no differences between the average scores for the Dementia Questionnaire for Mentally Retarded Persons Sum of Social (DMR-SOS), DMR Sum of Cognitive (DMR-SCS) and the Brief Praxis Test (BPT) administered in-person and by telemedicine. - a greater proportion of persons with Down Syndrome assessed by telemedicine (50%) were in the “severe to profound range of developmental disability” than those assessed in-person (21%). - no significant difference in the proportion with Down Syndrome diagnosed with DAT in-person (27.6%) vs telemedicine (32.8%). - CT brain scans were more prevalent than MRI studies in the rural settings - when comparing neurological tests, BPT was more effective in predicting DAT in persons with Down Syndrome than DMR-SOS and DMR-SCS.
McEachern et al. 2008 Canada	Instrument validation study (71 rural or remote persons with possible dementia aged ≥ 42 years) Compare telehealth and in-person MMSE scores	not provided	- MMSE scores did not differ significantly when administered in-person (22.3) or by telehealth (22.7). - the Bland-Altman method indicated that telehealth and in-person MMSE scores did not differ significantly (-0.37).
Morgan et al. 2009	see Diagnostic Processes theme above		
Shores et al. 2004 United States	Prospective cohort as classified by study’s authors (16 residents of two Veterans’ Homes in the US state of Washington) Compare diagnostic reliability of telemedicine and in-person assessments for dementia, as well as patient satisfaction with telemedicine	not provided	- 100% agreement on telemedicine and in-person dementia diagnoses, including dementia subtypes. - most patients preferred telemedicine to travelling for an in-person assessment, understood the telemedicine physician, and felt that the telemedicine exam afforded them sufficient privacy. - most geriatric psychiatrists indicated that the technology worked well most of the time and often prompted new recommendations for patient care.

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Vestal et al. 2006 United States	Instrument validation study (10 memory clinic patients with mild Alzheimer’s disease aged \geq 68 years in the US state of Arkansas) Compare effectiveness of language assessment in mild Alzheimer’s patients using telemedicine and in-person assessments	not provided	<ul style="list-style-type: none"> - telemedicine is effective for “conducting language screening in elderly persons at risk for dementia”. - most patients were highly satisfied with telemedicine equipment. - since the telemedicine and in-person assessments were conducted in the same facility, the patients could not indicate their satisfaction with time and travel saved by telemedicine assessment. - the language screening tests evaluated in this study were particularly effective for screening early dementia
Long-term care			
Gessert and Calkins 2001 United States	Health service evaluation (4847 nursing home residents with severe cognitive impairment aged \geq 65 years in the US state of Kansas, including 1,770 urban, 1,315 midsize, and 1,762 rural residents) Compare use of feeding tubes in rural/midsize/urban nursing homes	Urban counties: in metropolitan statistical areas Midsize counties: >20,000 urban population or >2,500 urban population that adjoined a metropolitan area Rural counties: <20,000 urban population or <2,500 urban population that adjoined a metropolitan area.	<ul style="list-style-type: none"> - urban nursing homes were more likely to use feeding tubes near the end of life than midsize and rural nursing homes.
Gessert et al. 2006 United States	Health service evaluation (1886 rural nursing home residents with severe and chronic cognitive impairment, aged \geq 67 years, and 1824 urban nursing home residents with severe and chronic cognitive impairment, aged \geq 67 years in the US states of Minnesota and Texas) Investigate factors associated with the last 90 days of end-of-life medical services use by nursing home residents with severe and chronic cognitive impairment	Based on U.S. Department of Agriculture 1993 metro-nonmetro continuum county codes, rural counties included those coded 6-9.	<ul style="list-style-type: none"> - during end-of-life care (last 90 days of life), rural nursing home residents experienced a “lower intensity of medical care” than urban nursing home residents. - during end-of-life care (last 90 days of life), rural nursing home residents had a higher risk of hospitalization than urban nursing home residents.
Morgan et al. 2002 Canada	Survey, focus groups, and chart review Study was conducted in 7 nursing homes (NHs) in one rural health district. Methods: survey of 110 NH (RNs, nursing aides, activity workers), two focus groups with NH staff (RN, nursing aide and activity worker from each home), and a chart review of 186 residents. Evaluate the level of overall job strain among direct care staff in rural nursing homes and compare job strain among RNs, nursing aides, and activity workers in rural nursing homes	The rural health district had a population density of 3.4 persons per square mile, and met the definition of a ‘frontier’ area that had 6 or fewer persons per square mile	<ul style="list-style-type: none"> - reported job strain varied by staff category - nursing aides indicated significantly more job demands than activity workers - RNs were more likely than aides to report that they had enough time to do their work - nursing aides cared for 10 residents each on average during day shifts - nursing aides were unable to spend adequate time in socializing activities with residents - job strain among direct care staff was greatly due to a perception that they were offering residents inferior care

Table 1
Summary of formal care provider studies

Study and country	Study method, sample, and objective	Definition of rural or remote	Major findings
Morgan et al. 2003 Canada	Health service evaluation Study was conducted in 7 nursing homes (NHs) in one rural health district. Methods: observational evaluation of the physical environment, 2 focus groups with facility staff (RN, nursing aide and activity worker from each home), and a chart review of 186 residents. Evaluate the physical and social environments of rural nursing homes and investigate the challenges associated with the social and physical environments of rural nursing homes	Rural centres had a population of 15,000 or less.	<ul style="list-style-type: none"> - the 7 rural nursing homes scored highest on the Physical Environment Assessment Protocol (PEAP) measures of provision of privacy. - rural nursing home staff indicated problems in the social environment that included heavy workloads and lack of dementia specific education, and problems in the physical environment such as integration of residents with dementia and the general resident population. - study results support an interaction of organization, social, and physical environments in conceptual models of dementia care settings. - physical environment problems were largely associated with the lack of dementia special care units, including safety and noise levels.
Morgan et al. 2004 Canada	Health service evaluation Observational evaluation of physical environment of 16 rural nursing homes (NHs), 8 with special care units [SCUs] and 8 without SCUs, and survey of 15 nursing directors of rural NHs Compare the physical and social environments of rural NHs with and without SCUs, as well as measures concerning residents, staff, and family members	Rural centres had a population of 15,000 or less.	<ul style="list-style-type: none"> - the mean summary Professional Environmental Assessment Protocol (PEAP) score was higher, indicating greater supportive environments, among rural SCUs (76.6) than among rural integrated facilities (55.3). - scores were significantly higher among facilities with SCUs than among rural integrated facilities on 6 of the 9 dimensions of the PEAP - restraint use was higher in integrated (44%) than SCU facilities (18%) - the Nursing Unit Rating Scale mean scores were significantly higher (better) for SCU than integrated facilities on the specific measures of separation of residents with dementia and less negative sensory stimulation. - rural SCUs and rural integrated facilities indicated that staff shortages negatively affected dementia programs for residents.
Morgan et al. 2005 Canada	Semi-structured interviews (10 nursing directors of care of special care units [SCUs] in rural nursing homes) Describe the development of special care units in rural nursing homes	Rural centres had a population of 15,000 or less. The authors used this definition, rather than a definition of 10,000 or less, to include a greater number of nursing homes with special care units across the province.	<ul style="list-style-type: none"> - since not every rural nursing home had a special care unit, some rural residents must leave their home community - familiarity between staff and residents was a benefit in that staff could personalize residents' care, and a drawback in that staff felt hurt by residents' aggression. - rural staff shortages was a drawback in that it led to untrained staff working in rural SCU. Service and specialist inaccessibility was also a drawback and a benefit in that directors of rural SCUs had creative freedom in developing the units. - nursing directors of care for rural SCUs had heavy workloads, since they often managed more than one facility
Morgan et al. 2005	see Education theme above		
Neville et al. 2006	see Education theme above		