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Dementia Learning Needs Assessment for Sun Country Health Region

July 2014

SURVEY REPORT

List of abbreviations used throughout the report:

AD - Alzheimer's disease

ADRD - Alzheimer's disease and related dementias

ASOS - Alzheimer Society of Saskatchewan

CCA - Continuing Care Aide

CE - Continuing Education

GP - General Practitioner

GRIID - Gateway to Rural International Initiatives in Dementia

HC - Home Care

HCN/CM - Home Care Nurses, Case Managers, and Home Care Nurse/Case Managers

IT - Information Technology

MMSE - Mini Mental State Examination

RaDAR Team - Rural Dementia Action Research Team

RN - Registered Nurse

SCHR - Sun Country Health Region

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Executive Summary

The main purpose of this research study was to explore the current work activities and learning needs related to Alzheimer's disease (AD) and other dementias among Home Care staff in Sun Country Health Region. *For the purposes of the present report, Continuing Care Aides (CCAs) (n=41) comprise one group. The second group includes all other respondents and is referred to as the HCN/CM group (n=41).* See Introduction and Methods Page 7

Estimated percentage of current patients with dementia Page 11

The majority of Continuing Care Aides (CCAs) and Home Care Nurses, Case Managers, and Home Care Nurse/Case Managers (HCN/CMs) estimated that more than 30% of their patients had dementia due to AD or another cause.

Adequacy of community support services for persons with AD or other dementias Page 12

Sixty-six percent (66%) of CCAs compared with 18% of HCN/CMs reported that their community has adequate support services for persons with AD or other dementias.

Comments on the effects of inadequate community support services on patient care Page 10

Three main issues emerged from respondents' comments regarding the impact of inadequate community services: *Patient issues* included late disease detection, increased travel to access services, lower quality of life, increased safety risks, risk for earlier institutionalization, and possible loss of relationships due to relocation. *Family issues* included lack of education, poor coping abilities, increased stress, health problems, and risk for burnout mainly due to lack of respite services. *Staff issues* included fewer education opportunities, greater isolation, lower quality of life, and increased workload and risk of burnout.

Adequacy of support and resources to provide patient- and family-centred care Page 15

The majority of HCN/CMs and CCAs agreed that they receive adequate support from a variety of different sources (e.g., adequate supervisor support, adequate communication with Home Care colleagues). However, a minority of CCAs reported adequate time, opportunities to pursue additional training, and services and resources from the health region, and a minority of HCN/CMs reported adequate communication with colleagues outside of Home Care (e.g., family physicians).

Regular current work activities related to patients with AD and other dementias **Page 16**

Among HCN/CMs and CCAs, three of the five most frequently reported regular work activities were the same activities for both groups: ‘assessing risk for falls’, ‘recognizing changes in patients’ cognitive function’, ‘with patients/families, discussing safety issues’.

Perceived competence in performing work activities related to Alzheimer’s disease (AD) and other dementias **Page 16**

A notable proportion of HCN/CMs (49% and over) perceived their competency to be at the novice/beginner level with respect to five of 20 work activities related to AD and other dementias: ‘recognizing differences between dementia subtypes’, ‘with patients/families, discussing legal issues’, ‘assisting with daily living activities’, and ‘with patients/families, discussing anticipated changes as the disease progresses’, and ‘detecting early symptoms of ADRD’. Among CCAs, perceived novice/beginner competency levels were most frequent (51% and over) with regard to 12 of 20 work activities related to AD and other dementias, including: ‘with patients/families, discussing legal issues’, ‘recognizing differences between dementia subtypes’, and ‘evaluating cognitive status with a standardized cognitive test’.

Interpretation of regular current work activities and competence **Page 19**

HCN/CMs regularly performed the activities of ‘assessing functional ability in patients’, ‘with patients/families, discussing anticipated changes as the disease progresses’, and ‘with patients/families, discussing legal issues’, yet a notable proportion of this group (45% and over) perceived their competency to be at a novice/beginner level with respect to these work activities. The majority of CCAs reported regularly ‘detecting early symptoms of ADRD’, ‘managing nutrition and hydration issues’, and ‘providing palliative care’. However, many CCAs (i.e., 30% and over) reported a perceived novice/beginner level of competency in these work activities.

Top 5 education topics in AD and other dementias **Page 20**

The topics ranked in the top 5 among HCN/CMs were ‘recognizing differences between dementia subtypes’ (Rank 1, 76%), ‘with patients/families, discussing anticipated changes as the disease progresses’, ‘detecting early symptoms of AD and other dementias’ (Rank 2, 54%), ‘with families, discussing strategies to manage behavioural symptoms in patients’ (Rank 3, 39%), ‘evaluating cognitive status with a standardized cognitive test’, ‘with patients/families, discussing legal issues’, ‘with families, discussing strategies for effectively communicating with patients’ (Rank 4, 37%), and ‘managing behavioural symptoms in patients’ (Rank 5, 34%). The topics ranked in CCAs’ top 5 were ‘recognizing differences between dementia subtypes (Rank 1, 66%), ‘detecting early symptoms of AD and other dementias’ (Rank 2, 54%), ‘recognizing changes in patients’ cognitive function’ (Rank 3, 39%), ‘assessing functional ability in patients’, ‘providing palliative care for patients’ (Rank 4, 37%),

and ‘managing behavioural symptoms in patients’, ‘with patients/families, discussing anticipated changes as the disease progresses’ (Rank 5, 34%).

Interpretation of top 5 education topics and competence

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The top ranked topic that HCN/CMs were interested in learning more about, ‘recognizing differences between dementia subtypes’, was also the top-ranked topic in terms of perceived novice/beginner competence among this group. The top ranked topic that CCAs were interested in learning more about, ‘recognizing differences between dementia subtypes’ was also perceived by the majority of CCAs to be a work activity which they performed at a novice/beginner competency level.

Interest in Continuing Education (CE) program formats

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CCAs and HCN/CMs were equally likely to be most interested in attending CE programs held in a local community. Both groups were equally likely to be least interested in computer-based CE program formats.

Barriers to attending a CE program (on any topic)

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The top-ranked barriers among HCN/CMs were ‘low staffing levels’ and ‘geographically difficult to access’ CE programs. Tied for second place among HCN/CMs were ‘insufficient time during work hours to attend’ and ‘insufficient personal time to attend outside of work hours’. ‘Low staffing levels’ also ranked first among CCAs. Among CCAs, ‘insufficient time during work hours to attend’ also ranked second.

Enablers to attending a CE program on any topic

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Locally offered CE programs and paid time off to attend CE programs were the two primary enablers suggested by Home Care staff. Secondary enablers included improved advertising of CE opportunities, adequate staffing to allow a group of staff to attend CE programs together, offering CE via Telehealth, and awarding certificates for CE program participation. Secondary enablers also included employer action on ideas that emerge from staff as a result of CE participation, financial support from employers, and managers making CE program arrangements for staff.

Introduction

A recent report estimates the global number of people currently living with dementia (prevalence) to be 44 million. This figure is projected to rise by 70% to 75 million in the next 15 years (Prince et al. 2013). Population aging and cardiovascular risk factors, which are both on the rise worldwide but particularly in East Asia and sub-Saharan African countries, are leading to a faster-growing rate of dementia prevalence than previously suggested.

Research suggests that health care providers exhibit high levels of uncertainty in providing dementia care (Pimlott et al. 2009), a finding that is supported by specialist referral rates of over 80% (Pimlott et al. 2006). Underdiagnosis is a common challenge; 31% to 69% of patients in primary care with dementia do not receive a formal, i.e., documented diagnosis; formal diagnosis is less likely to occur among mild than moderate or severe cases (Boustani et al. 2003; Bradford et al. 2009; van den Dungen et al. 2012).

Without a formal diagnosis, individuals and their families are less likely to access the services and community resources they require. The three main barriers to a formal diagnosis are (1) patient and caregiver issues such as a lack of symptom awareness, lack of support to seek help, attitudes such as resistance to diagnosis and perceived stigma, (2) health care professional attitudes such as therapeutic nihilism, knowledge and adherence to clinical practice guidelines, diagnostic uncertainty and difficulties in diagnosis disclosure, and (3) health care system factors such as limited time to conduct consultations and limited access to diagnostic information and resources (Bradford et al. 2009; Koch and Iliffe 2010; van den Dungen et al. 2012).

Improving care at the point of diagnosis as well as across the care continuum is an international as well as local concern. Identifying the best ways to support individuals with dementia living in the community is a dilemma faced by health regions in Saskatchewan as well as health systems across Canada and elsewhere.

The Sun Country Health Region Dementia Working Group was formed as part of the recent SCHR Dementia Hoshin to address some of the challenges currently facing individuals with dementia and their families in the health region. A key initiative of the SCHR Dementia Working Group was an assessment of the educational needs of health care providers regarding dementia care, specifically home care providers. The assessment also examined home care providers' perspectives on their regular work activities and perceived competence related to dementia care, as well as available community support services.

The *Dementia Learning Needs Assessment* for Sun Country Health Region was conducted by the Rural Dementia Action Research (RaDAR) Team (see the end of the Report for more information about RaDAR).

Methods

The *Dementia Learning Needs Assessment* for Sun Country Health Region was conducted by the Rural Dementia Action Research (RaDAR) Team (see the end of the Report for more information about RaDAR).

The main purpose of this research study was to explore the current work activities and learning needs related to Alzheimer's disease (AD) and other dementias among Home Care staff in Sun Country Health Region.

The *Dementia Learning Needs Assessment* followed a rigorous process of development. First, we conducted a literature review during July and August, 2013, which informed the first draft of the questionnaire. The purpose of the literature review was to identify concepts and instruments for the *Needs Assessment*. We reviewed 25 peer-reviewed articles and one report, and found that previous studies had examined educational needs, knowledge, attitudes, diagnosis and management and referral practices, as well as confidence and competence (see Appendix A). We also found scales that had been developed and tested to measure knowledge and attitudes, and that these scales had been tested on a range of health care providers (e.g., GPs, Nurses, Specialists, Physical Therapists, Nursing Home staff).

The literature review also included best practice recommendations from a 2009 Alzheimer's Association report, *Dementia Care Practice Recommendations for Professionals Working in a Home Settings*. These practice recommendations fell into six main areas: personal care, safety and personal autonomy, home safety, end-of-life care, Home Care Provider training, and special topics. The recommendations suggested that home care providers should have the training necessary to recognize the 10 warning signs of early dementia and communicate any changes in patients to their supervisors. It was also recommended that care providers understand how to communicate effectively with patients and their families, and that family and support services from the community be included as part of the care team. Recommendations also included recognizing behavioral symptoms in patients and communicating about these symptoms to supervisors, providing the proper information to families, and regularly updating care plans as patients' needs change.

Following the literature review, we conducted focus groups with 11 Sun Country Home Care staff to better understand their work activities involved in caring for individuals with dementia. This step was followed by a second draft of the questionnaire, which was reviewed for content by members of the RaDAR Team. The third draft of the questionnaire became the final survey.

Data collection for the Dementia Learning Need Assessment took place by mail survey during January to March, 2014. The survey package included a cover letter, survey questionnaire, consent form, and self-addressed stamped envelope. The 10-page survey consisted of nine major sections, the results of which are described in the present report. This study received approval from the Behavioural Research Ethics Board of the University of Saskatchewan (BEH #13-133) and Regina Qu'Appelle Health Region (REB #13-94).

Note. A p value of <0.05 is interpreted as 'statistically significant' and indicates that this result would have occurred by chance on less than one occasion in 20.

Demographics of respondents

Individuals who were eligible to complete the survey were Home Care Nurses (HCN), Case Managers (CM), and Continuing Care Aides (CCA). Of 111 eligible respondents, 82 individuals completed and returned the survey (74% response rate).

Respondents' demographic characteristics are detailed in Table 1. The majority of respondents were women (94%) and the average age was 45.1 years (range 19-66, SD=12.4).

Half of the respondents were Continuing Care Aides (50%), one in four were Home Care Nurses (24%), and one in four were either Case Managers (12%) or Home Care Nurses/Case Managers (13%). *For the purposes of the present report, CCAs (n=41) comprise one group. The second group includes all other respondents and is referred to as the HCN/CM group (n=41).*

Most staff had been in their current position for more than 5 years (56%). Sixteen percent (16%) had been in their position for less than 1 year and an equivalent proportion had been in their current position for 20 years or longer.

The average length of time elapsed since respondents had completed their highest level of health care education was 18.3 years (range 1-46, SD=11.2).

Table 1 Demographic characteristics of survey respondents

Characteristic	n (%)
Age^a	
Average age (range, SD)	45.1 (19-66, 12.4)
Gender	
Men	2 (3)
Women	77 (94)
Missing	3 (4)
Current Position	
Continuing Care Aide	41 (50)
Home Care Nurse	20 (24)
Case Manager	10 (12)
Home Care Nurse/Case Manager	11 (13)
Years in Current Position	
Less than 1 year	13 (16)
1-5 years	23 (28)
6-9 years	14 (17)
10-20 years	19 (23)
20 years or more	13 (16)
Years since completing highest health care education^b	
Average years (SD, range)	18.3 (1-46, 11.2)

^a N=79

^b N=72

Approximately what percentage of your current patients would you estimate have dementia due to AD or other dementias?

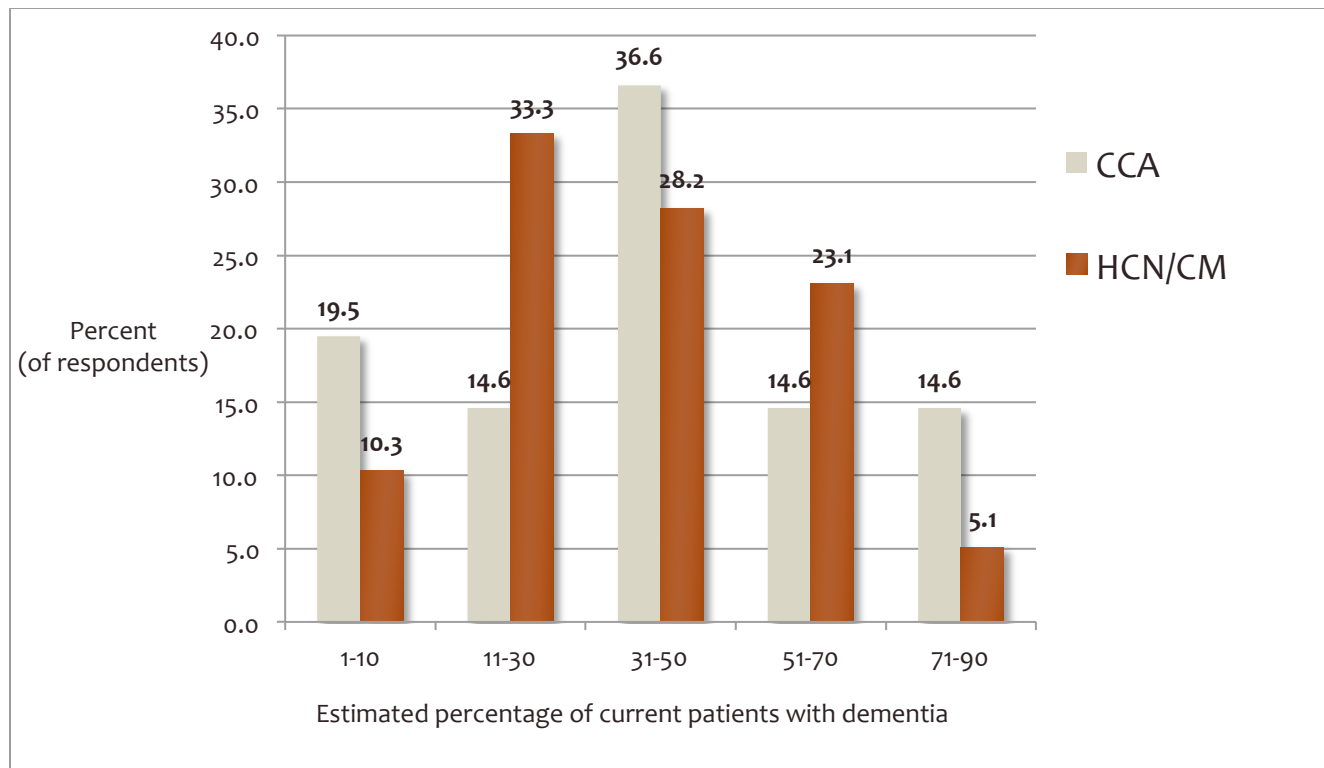


Figure 1 Estimated percentage of current patients with dementia due to AD or another cause (including those not yet diagnosed)

Respondents were asked to estimate the percentage of their current patients* with dementia due to AD or another cause, including those at any stage of cognitive impairment who may not yet have been diagnosed by a health care professional.

As shown in Figure 1, the majority of CCAs (65.8%) and HCN/CMs (56.4%) estimated that more than 30% of their patients had dementia due to AD or another cause. These estimates did not differ significantly between the two staff groups.

*Respondents were instructed to note that the term ‘patients’ referred to care recipients in general, and included clients, patients, and/or residents. ‘Family’ referred to families and family members, and included spouse, children, relatives, friends, and neighbors.

Does your community have adequate support services for persons with AD or other dementias?

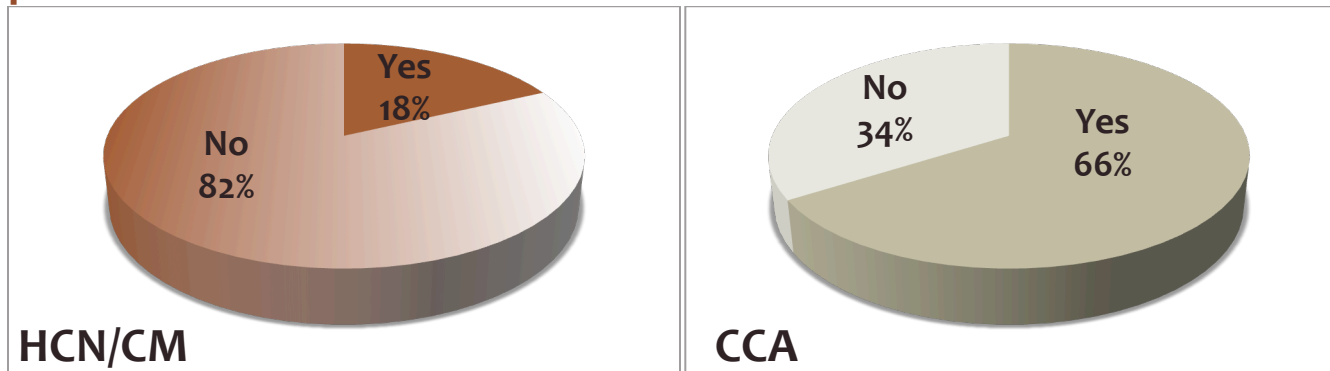


Figure 2 Perceived adequacy of community support services for persons with AD or other dementias

When asked whether their community has adequate support services for persons with AD or other dementias, CCAs (66%) were 3.7 times more likely than HCN/CMs (18%) to report that their community has adequate support services (Figure 2). This difference between the two groups was significantly different ($p < 0.05$).

How does the lack of adequate services affect the care you provide to patients with AD or other dementias?

Respondents who answered ‘no’ to the previous question were given the opportunity to comment on the effect that the lack of such services has on the care they provide to patients with AD or other dementias. Three main issues emerged from respondents’ comments. These issues concerned impacts on patients, caregivers, and staff as a result of inadequate support services. **Patient issues** included late disease detection, increased travel to access services, lower quality of life, increased safety risks, risk for earlier institutionalization, and possible loss of relationships due to relocation. **Family issues** included lack of education resources, poor coping abilities, increased stress, health problems, and risk for burnout mainly due to lack of respite services. **Staff issues** included fewer education opportunities, greater isolation, lower quality of life, increased workload and risk of burnout.

Respondent Comments:

No doctor to visit clients in own community. Clients have to rely on getting to another town or go to the closest cities. Sometimes just the lack of staffing in rural areas.

No doctor or ER in our community, HHAs would benefit with ongoing training in dealing with dementias. Very limited access to mental health care in our community. Not always sure what to look for, warning signs of dementia. We work isolated and alone.

No Day programs available to provide a break for families living with a Dementia patient, lack of respite beds, no Home Care services during the hours of 1615-0800. Home Care RN works only 2 days a week. No Assisted Living apartments available in our area.

Not enough services are available or helpful to clients with dementia. Families struggle with keeping their family members safe and rely heavily on Home Care and community people.

Late detection of Alzheimer's or Dementias. Little to no support for families.

The support services are adequate to a certain level. Patients with dementia and Alzheimer's disease usually get referred to the nursing home. They (nursing home) cannot handle the extreme cases well because of lack of adequate facility and number of staff. The patient then is transferred to Weyburn where they have a specially designed facility and program and adequate staff for the patient's needs.

Because we don't have places for people with Alzheimer's to go (yes there is Nursing Home but sometimes that is not the answer). It means that the families that can afford it move loved ones an hour or more away and then the client loses contact with life long friends and I know that would make me depressed.

Family of clients experiencing burnout more often; no private services available to family for respite, no education for family or staff; no awareness for available assistance or education.

Many families have questions regarding their family members with dementia and we do not have the resources at hand to provide care to the client and families, therefore it's harder to make those connections, longer to build trust and can increase their frustrations.

We are 2-3 hours away from a major facility.

More education and support needed for caregivers. Cost of services and access to in home respite can be factors.

This is difficult in the smaller rural areas as most of our clients lack transportation to get to the urban centres where there is the support.

Not a lot of support for 24 hours-7 days a week assistance. Huge risk for family/primary care burnout.

Mental Health services, Telehealth, Respite Care - these are some services provided. Need more support service providers that can be contact for families dealing with disease such as Dementia and Alzheimer's.

There is a need for respite care - not enough HC staff to provide. Does not directly affect my services, but may cause patients to be institutionalized sooner and cause stress and health problems to caregiver.

It would be nice to have more support in the client's home in the Estevan area.

Lack of support for client's family leads to burnout. Clients could do better in home if their support people had more ideas on how to support them. Some situations in the home could be better handled if family knew how to properly intervene.

More supporting the spouses of clients with Alzheimer's disease than helping the client who are diagnosed. By providing housekeeping, bathing, and respite.

No one/nowhere to refer them to.

Although it is getting better thanks to ASOS and SCHR, services are still sporadic and not local.

Our community has some supports but minimal. Often programs are filled up such as Day Respite Program.

I wouldn't say it affects the care, however if a day program was available I believe that it would greatly enhance quality of life for the client as well as care staff and family members.

Telehealth sessions available. Mental Health Services. We have long term care and there are respite beds offered. There are no specific facilities or care programs. Everything is a travelling service as we are isolated. I think we could provide better care for clients and families if there was someone easily accessible to contact and get information from.

Frustration for ones who have the disease and also for ones who don't know how to communicate with ones who have dementia. Need activities to keep them active as much as possible. We all need to be educated on empathy, compassion, and patience.

Early detection, compassionate and educated care while accessing health care services (inpatient in acute care).

Once they are diagnosed they are kind of left on own unless seeks home care support. No support groups.

Support groups would be beneficial to help families cope. Education has been available in Telehealth but does not appear to be utilized.

We have some Telehealth meetings on Alzheimer's disease for family and people who are interested. But not enough.

Occasional telehealth seminars (sometimes hard for families to attend); referral to Alzheimer Society

No support groups; difficult for families to obtain resource materials; education for families.

More resources have become available through First Link recently but this is still new to the community.

A new program has been introduced but so far most family don't think they can help them because the family has tried everything. Need more public education of the Dementia and Alzheimer's Programs.

Extra time needed to manage client's day to day needs as a nurse especially if no caregiver in the home.

Increases work load, affects client's family to care for client in home.

Adequacy of support and resources to provide patient- and family-centred care to patients with AD or other dementias

Respondents were provided with the following definition of patient- and family-centred care: “Providing respectful, compassionate, culturally responsive care that meets the needs, values, cultural backgrounds and beliefs, and preferences of patients and their family members in diverse backgrounds by working collaboratively with them.” (SK Ministry of Health, 2011)

As shown in Table 2, the majority of HCN/CMs and CCAs agreed that they received adequate support and resources from seven of 10 different sources to provide patient- and family-centred care to patients with AD or other dementias. However, only a minority of HCN/CMs agreed that they have ‘enough time available during the workday’ (42%), ‘adequate opportunities to pursue additional training’ (42%), and ‘adequate services and resources’ from the health region (32%). A minority of CCAs agreed that they have an ‘adequate amount of communication with colleagues outside of Home Care’, such as family physicians or other health care providers (41%).

CCAs were significantly more likely than HCN/CMs to agree that they have ‘enough time available during the workday’ (83% vs. 42%) and ‘adequate services and resources’ from the health region (70% vs. 32%) to provide patient- and family-centred care.

Table 2 Adequacy of support and resources to provide patient- and family-centred care to patients with AD or other dementias*

Resource	HCN/CM n (%)	CCA n (%)	p-value
My work experience has adequately prepared me	30 (73)	38 (93)	0.06
I have received adequate training	25 (61)	30 (73)	0.38
I have adequate support from my supervisor	31 (76)	37 (90)	0.20
I have an adequate amount of communication with my Home Care colleagues	34 (83)	38 (93)	0.52
I have an adequate amount of communication with my colleagues outside of Home Care (family physicians or other health care providers)	22 (54)	17 (41)	0.40
I have adequate access to patient information	33 (81)	25 (63)	0.42
I have an adequate understanding of the actions I need to take	28 (68)	34 (83)	0.42
I have enough time available during the workday	17 (42)	34 (83)	<0.05**
I have adequate opportunities to pursue additional training	17 (42)	21 (51)	0.71
The health region provides adequate services and resources to support me	13 (32)	28 (70)	<0.05**

*Strongly agree/Agree

**Difference between HCN/CM and CCA groups is significant at $p < 0.05$ level

Regular current work activities related to AD and other dementias

Given a list of 20 work activities related to AD and other dementias, Home Care staff indicated how often such activities are part of their current work. Responses included ‘never’, ‘rarely’, ‘sometimes’, ‘often’, and ‘very often’. For the present report, responses of ‘very often’, ‘often’, and ‘sometimes’ were grouped together to represent regular current work activities. These responses are depicted in Figure 3.

Among HCN/CMs and CCAs, three of the five most frequently reported regular work activities were the same activities for both groups. As shown in Figure 3, the five most frequently performed regular work activities among HCN/CMs included ‘recognizing changes in patients’ cognitive function’ (98%), ‘with patients/families, discussing safety issues’ (95%), ‘with families, discussing strategies for managing patients’ personal care’ (90%), ‘assessing risk for falls’ (90%), and ‘detecting early symptoms of ADRD’ (88%). Among CCAs, the five most frequently performed work activities among CCAs included ‘assessing risk for falls’ (100%), ‘assisting with personal care’ (100%), ‘recognizing changes in patients’ cognitive function’ (98%), ‘assisting with daily living activities (97%), and ‘with patients/families, discussing safety issues’ (78%).

Among HCN/CMs, the two least frequently performed work activities were ‘recognizing differences between dementia subtypes’ (17%) and ‘assisting with daily living activities’ (10%). Among CCAs, the two least frequently performed work activities were ‘evaluating cognitive status with a standardized cognitive test’ (10%) and ‘with patients/families, discussing legal issues’ (5%).

When taking into account 20 work activities related to AD and other dementias, HCNs/CMs were significantly more likely ($p<0.05$) than CCAs to regularly perform 11 of the activities as part of their current work, e.g., ‘detecting early symptoms of ADRD’ (88% vs. 68%). CCAs were significantly more likely ($p<0.05$) than HCN/CMs to regularly perform two of the 20 activities as part of their current work, specifically ‘assisting with personal care’ (100% vs. 27%) and ‘assisting with daily living activities (97% vs. 10%).

Perceived competence in performing work activities related to AD and other dementias

Home Care staff were provided with the same list of 20 work activities as described above (and in Figure 3), and indicated their current level of competence in performing these activities with patients with AD and other dementias. Responses included ‘not applicable’, ‘novice (lowest level)’, ‘competent’, ‘proficient’, and ‘expert (highest level)’. For the present report, the responses of ‘not applicable’, ‘novice’, and ‘beginner’ were grouped together to represent a novice/beginner competence level. These responses are depicted in Figure 4.

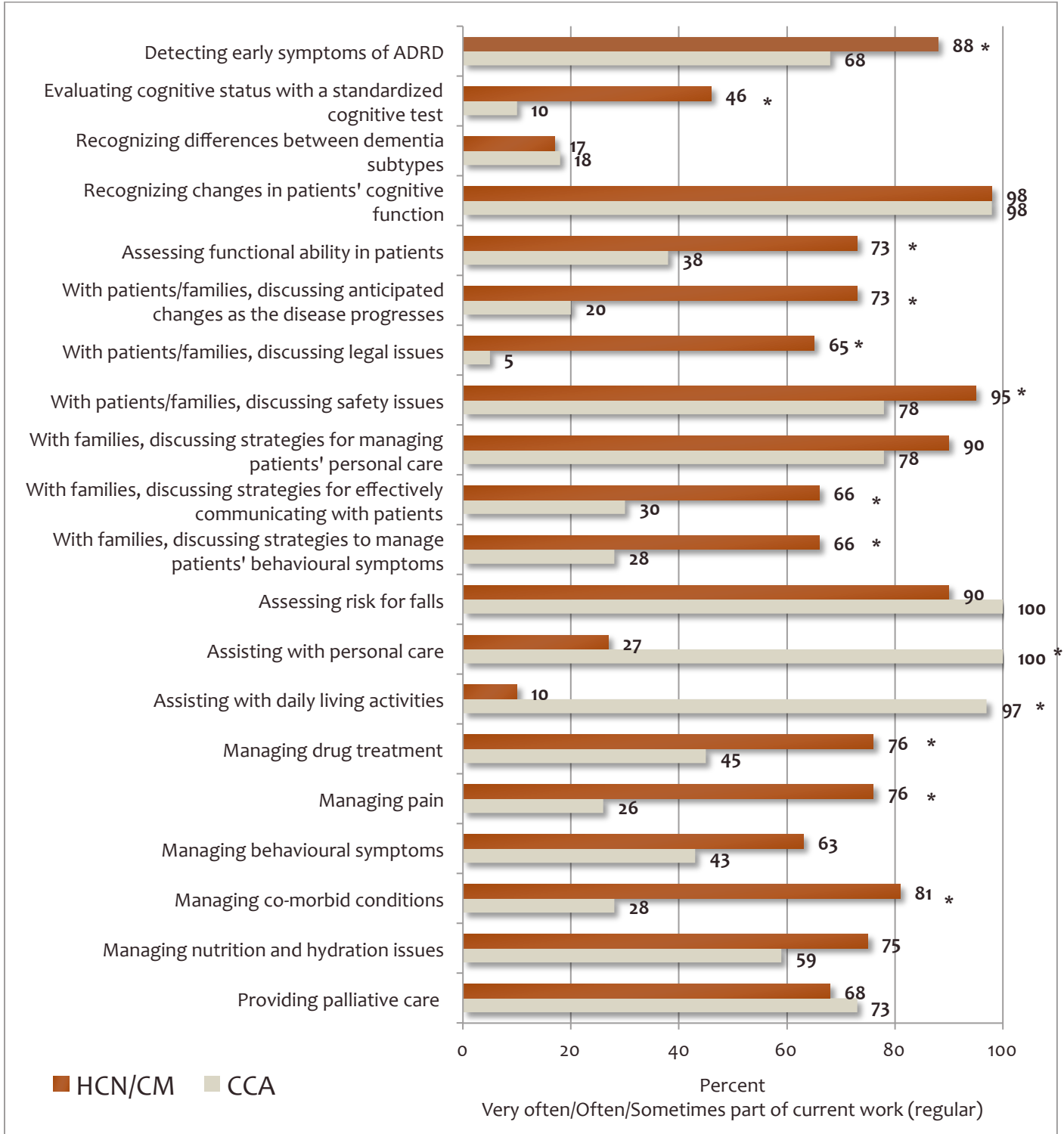


Figure 3 Frequency of regular current work activities related to AD and other dementias

*Difference between HCN/CM and CCA groups is significant at $p < 0.05$ level

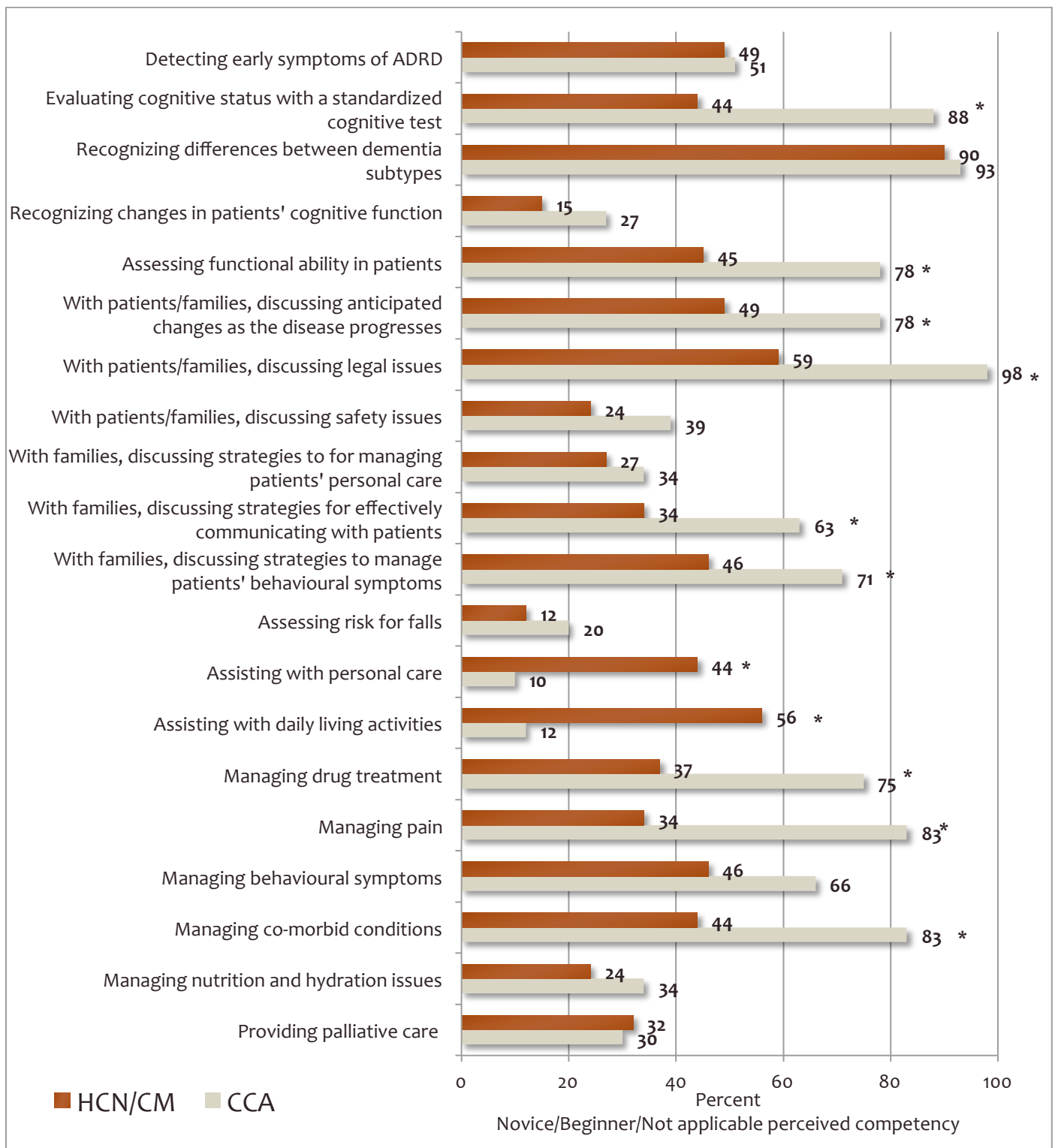


Figure 4 Perceived competency of current work activities related to AD and other dementias

*Difference between HCN/CM and CCA groups is significant at $p < 0.05$ level

As shown in **Figure 4**, CCAs were significantly more likely than HCN/CMs to perceive their competency to be at a novice/beginner level in 11 of 20 work activities (e.g., ‘with patients/families, discussing legal issues’).

A notable proportion of HCN/CMs (49% and over) perceived their competency to be at the novice/beginner level with respect to five of 20 work activities related to AD and other dementias: ‘recognizing differences between dementia subtypes’ (90%), ‘with patients/families, discussing legal issues’ (59%), ‘assisting with daily living activities’ (56%), and ‘with patients/families, discussing anticipated changes as the disease progresses’ (49%) and ‘detecting early symptoms of ADRD’ (49%). Among CCAs, perceived novice/beginner competency levels were most frequent (51% and over) with regard to 12 of 20 work activities related to AD and other dementias, including: ‘with patients/families, discussing legal issues’ (98%), ‘recognizing differences between dementia subtypes’ (93%), and ‘evaluating cognitive status with a standardized cognitive test’ (88%).

CCAs were significantly more likely ($p>0.05$) than HCN/CMs to perceive their competency to be at a novice/beginner level in nine of 20 work activities. HCN/CMs were significantly more likely ($p>0.05$) than CCAs to perceive their competency level to be novice/beginner in two of 20 activities: ‘assisting with personal care’ (44% vs. 10%) and ‘assisting with daily living activities’ (56% vs. 12%).

Among HCN/CMs, perceived novice/beginner competency levels were lowest with respect to ‘recognizing changes in patients’ cognitive function’ (15%) and ‘assessing risk for falls’ (12%), i.e., this staff group felt most competent in performing these activities. Novice/beginner competency levels were lowest among CCAs with regard to ‘assisting with daily living activities’ (12%) and ‘assisting with personal care’ (10%), indicating that CCAs felt most competent in these activities.

Interpretation of regular current work activities and competence

Among HCN/CMs, a sizable majority considered ‘detecting early symptoms of ADRD’ to be a regular work activity (88%), however approximately half perceived their competence to be at a novice/beginner level with respect to this activity (49%). Furthermore, HCN/CMs regularly performed the work activities of ‘assessing functional ability in patients’ (73%), ‘with patients/families, discussing anticipated changes as the disease progresses’ (73%), and ‘with patients/families, discussing legal issues’ (65%), yet a notable proportion of this group perceived their competency to be at a novice/beginner level with respect to these work activities (45%, 49%, and 59%, respectively).

Among CCAs, most staff reported regularly ‘detecting early symptoms of ADRD’ (68%), ‘managing nutrition and hydration issues’ (59%), and providing palliative care’ (73%). However, many CCA’s reported a perceived novice/beginner level of competency in these work activities (51%, 34%, and 30%).

Top 5 education topics in AD and other dementias

Home Care staff were provided with the same list of 20 work activities (as shown in Figures 3 and 4) and asked to identify 5 work activities (topics) that they would like to learn more about. Results were rank ordered by frequency of 'yes' responses. *Note that the frequency counts for some education topics were equivalent, resulting in 'ties' in rankings.*

Table 3 shows the topics in rank order, by frequency of 'yes' responses. The topics ranked in the top 5 among HCN/CMs were 'recognizing differences between dementia subtypes' (Rank 1, 76%), 'with patients/families, discussing anticipated changes as the disease progresses', 'detecting early symptoms of AD and other dementias' (Rank 2, 54%), 'with families, discussing strategies to manage behavioural symptoms in patients' (Rank 3, 39%), 'evaluating cognitive status with a standardized cognitive test', 'with patients/families, discussing legal issues', 'with families, discussing strategies for effectively communicating with patients' (Rank 4, 37%), and 'managing behavioural symptoms in patients' (Rank 5, 34%).

The topics ranked in CCAs' top 5 were 'recognizing differences between dementia subtypes (Rank 1, 66%), 'detecting early symptoms of AD and other dementias' (Rank 2, 54%), 'recognizing changes in patients' cognitive function' (Rank 3, 39%), 'assessing functional ability in patients', 'providing palliative care for patients' (Rank 4, 37%), and 'managing behavioural symptoms in patients', 'with patients/families, discussing anticipated changes as the disease progresses' (Rank 5, 34%).

Compared to CCAs, HCN/CMs were significantly more interested ($p<0.05$) in learning more about 'discussing legal issues' (37% vs. 10%), and 'managing drug treatment in patients' (22% vs. 2%).

Interpretation of top 5 education topics and competence

The top ranked topic that HCN/CMs were interested in learning more about, 'recognizing differences between dementia subtypes' (Rank 1, 76%), was also the top-ranked topic in terms of perceived novice/beginner competence among this group (90%). Also in the top 5 education topics among HCN/CMs were 'with patients/families, discussing legal issues' (Rank 4, 37%), a work activity that the majority of HCN/CMs perceived themselves to perform at a novice/beginner competency level (59%). Tied for the second-ranked education topic (54%) were the activities of 'with patients/families, discussing anticipated changes as the disease progresses' and 'detecting early symptoms of AD and other dementias', two topics which were identified as novice/beginner competency level work activities by nearly half of HCN/CMs (49%).

The top ranked topic that CCAs were interested in learning more about, 'recognizing differences between dementia subtypes' (Rank 1, 66%) was also perceived by the majority of CCAs to be a work activity that they performed at a novice/beginner competency level (93%). 'Assessing functional ability in patients' ranked fourth in terms of education topics of interest among CCAs and was identified by a sizable majority (78%) as a novice/beginner competency level work activity.

Table 3 Would like to learn more about AD and other dementias topics*

AD and Other Dementias Topic	HCN/CM Rank (%)	CCA Rank (%)	p-value
Recognizing differences between dementia subtypes (e.g., AD, Lewy Body dementia, frontotemporal dementia, Vascular Dementia)	1 (76)	1 (66)	0.33
With patients and/or families, discussing anticipated changes as the disease progresses	2 (54)	5 (34)	0.08
Detecting early symptoms of AD and other dementias	2 (54)	2 (54)	1.00
With families, discussing strategies to manage behavioural symptoms in patients (e.g., mood changes, wandering, resisting care)	3 (39)	8 (24)	0.15
Evaluating cognitive status with a standardized cognitive test (e.g., MMSE, Clock Drawing Test)	4 (37)	6 (29)	0.48
With patients and/or families, discussing legal issues (e.g., competency, power-of-attorney, etc.)	4 (37)	13 (10)	<0.05**
With families, discussing strategies for effectively communicating with patients (verbally and nonverbally)	4 (37)	7 (27)	0.34
Managing behavioural symptoms in patients	5 (34)	5 (34)	1.00
Assessing functional ability in patients (using a standardized measure or tool)	6 (27)	4 (37)	0.34
Recognizing changes in patients' cognitive function	7 (24)	3 (39)	0.15
Managing drug treatment in patients	8 (22)	16 (2)	<0.05**
Providing palliative care for patients	9 (20)	4 (37)	0.09
Managing co-morbid conditions in patients (e.g., diabetes plus dementia, cancer plus dementia, etc.)	10 (12)	9 (22)	0.24
Managing pain in patients	11 (10)	11 (15)	0.50
With patients and/or families, discussing strategies for managing patients' personal care (e.g., bathing, oral care, dressing, grooming, or toileting)	12 (7)	10 (17)	0.18
With patients and/or families, discussing safety issues (e.g., food, bathroom, kitchen, accident prevention, and other home and general safety issues)	13 (2)	12 (12)	0.09
Assessing risk for falls in patients	13 (2)	14 (7)	0.31
Managing nutrition and hydration issues in patients	13 (2)	12 (12)	0.09
Assisting patients with personal care	14 (0)	14 (7)	0.08
Assisting patients with daily living activities (e.g., mobility, transportation, shopping, eating, or housework)	14 (0)	15 (5)	0.15

*Yes

**Difference between HCN/CM and CCA groups is significant at $p < 0.05$ level

Interest in Continuing Education (CE) program formats, specifically in relation to the topic of AD and other dementias

Figure 5 Interest in CE program formats

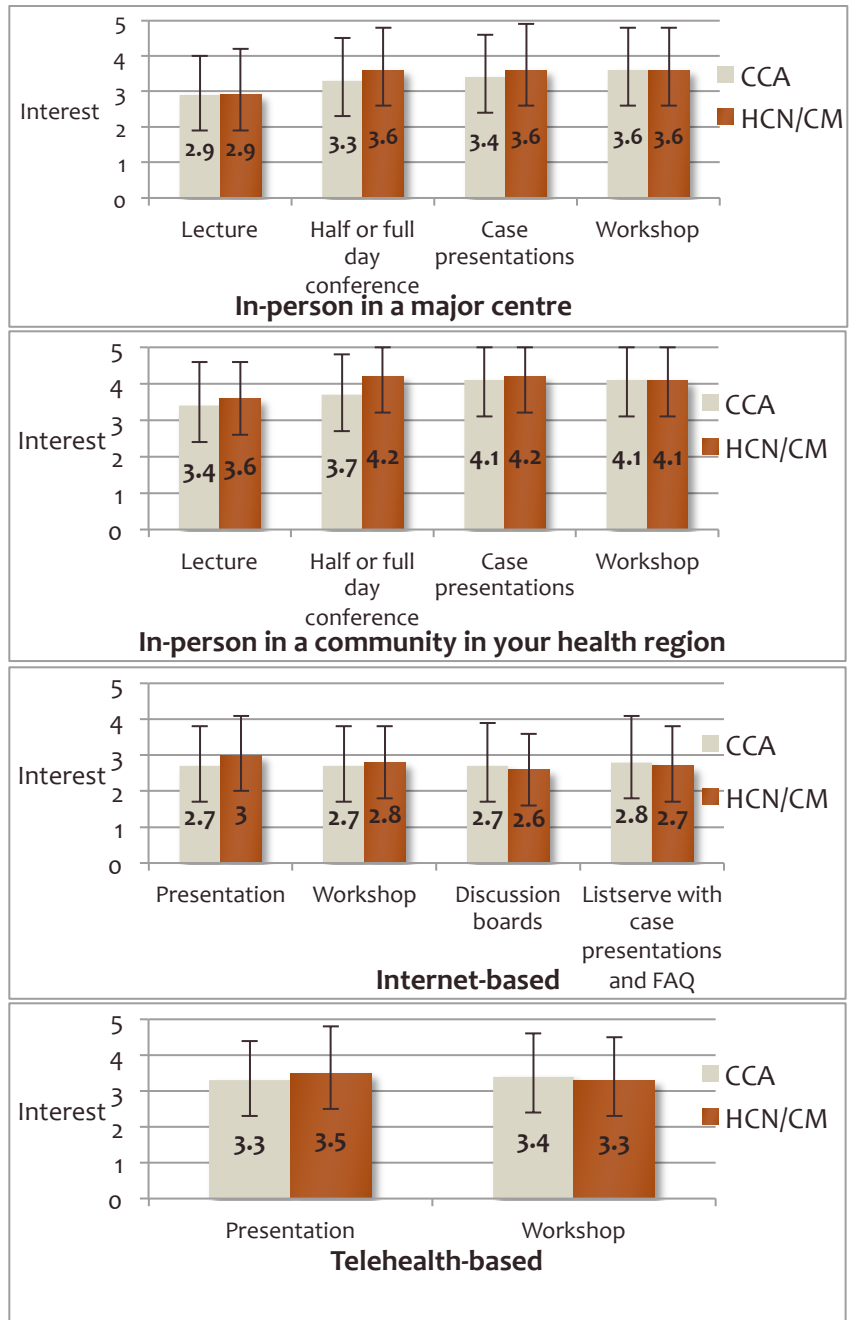
Home Care staff were asked to indicate their interest in five different program formats of Continuing Education (CE):

- 1) In-person in a major centre,
- 2) In-person in a community in their health region
- 3) Internet-based
- 4) Telehealth-based
- 5) Computer-based

Items were scored from 1 (very low) to 5 (very high), with higher scores indicating higher interest in a particular CE program format.

As shown in Figure 5, CCAs and HCN/CMs were equally likely to be most interested in attending CE programs held in a local community, with average scores for CCAs ranging from 3.4 to 4.1 and HCN/CMs ranging from 3.6 to 4.2.

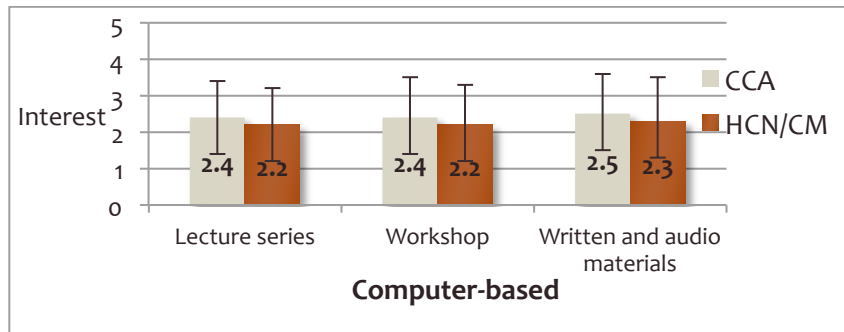
Both groups were equally likely to be least interested in



The lines that overlap the bars in the graphs indicate the standard deviation (SD) of each mean score, representing the dispersion of scores around the mean.

computer-based CE program formats, with average CCA scores ranging between 2.4 and 2.5 and HCN/CM scores ranging from 2.2 to 2.3.

Interest in particular CE program formats did not differ significantly between the two staff groups.



What are the barriers that keep you from attending a CE program (on any topic)?

Home Care staff were provided with a list of 14 items and asked to select all of the items that would be a barrier to attending a CE program (on any topic). Results were rank ordered by frequency of ‘yes’ responses.

Table 4 shows that the top-ranked barriers among HCN/CMs were ‘low staffing levels’ (44%) and ‘geographically difficult to access’ CE programs (44%). Tied for second place among HCN/CMs were ‘insufficient time during work hours to attend’ and ‘insufficient personal time to attend outside of work hours’ (39%). ‘Low staffing levels’ also ranked first among CCAs (46%). Among CCAs, ‘insufficient time during work hours to attend’ also ranked second.

Among HCN/CMs, the three lowest ranked barriers included ‘CE programs typically do not address my CE needs’ (5%), ‘personal health problems’ (2%), and ‘CE programs do not sufficiently improve my skills or knowledge’ (0). The lowest ranked barriers among CCAs included ‘inadequate Information Technology (IT) resources at work’ (5%), ‘inadequate IT resources at home’ (5%), and ‘personal health problems’ (2%).

Significant differences were found between HCN/CMs and CCAs with regard to two particular barriers. CCAs were significantly more likely ($p < 0.05$) than HCN/CMs to consider ‘participation in CE programs is not a formal requirement of employment’ (29% vs. 7%) and ‘CE programs typically do not address my CE needs’ (22% vs. 5%) as barriers to attending a CE program on any topic.

Table 4 Barriers to attending Continuing Education (CE) programs on any topic*

Barrier	HCN/CM Rank (%)	CCA Rank (%)	p-value
Low staffing levels (e.g., relief staff is unavailable)	1 (44)	1 (46)	0.82
CE programs are geographically difficult to access (require significant travel)	1 (44)	4 (24)	0.06
Insufficient time during work hours to attend	2 (39)	2 (39)	1.00
Insufficient personal time to attend (outside of work hours)	2 (39)	3 (29)	0.35
Low level of employer financial support	3 (27)	6 (20)	0.43
CE programs are generally not well advertised	4 (20)	7 (17)	0.78
Low level of employer encouragement	5 (17)	5 (22)	0.58
Other personal issues	6 (12)	8 (12)	1.0
Inadequate IT (Information Technology resources) at work	7 (10)	9 (5)	0.40
Inadequate IT resources at home	7 (10)	9 (5)	0.40
Participation in CE programs is not a formal requirement of employment	8 (7)	3 (29)	<0.05**
CE programs typically do not address my CE needs	9 (5)	5 (22)	<0.05**
Personal health problems	10 (2)	10 (2)	1.0
CE programs do not sufficiently improve my skills or knowledge	11 (0)	10 (2)	0.31

*Yes

**Difference between HCN/CM and CCA groups is significant at $p < 0.05$ level

What are the enablers/facilitators that would help you to attend a CE program on any topic?

Respondents were asked to describe enablers or facilitators that would help them to attend a CE program on any topic. Two primary and several secondary enablers emerged from respondents' comments. Locally offered CE programs and paid time off to attend CE programs were the two primary enablers described by Home Care staff. Secondary enablers included improved advertising of CE opportunities, adequate staffing to allow a group of staff to attend CE programs together, offering CE via Telehealth, and awarding certificates for CE program participation. Secondary enablers also included employer action on ideas that emerge among staff as a result of CE participation, financial support from employers, and managers making CE program arrangements for staff.

General Comments from Respondents

A family member had some type of dementia that was never acknowledged by her family doctor. There was no investigation or diagnosis. The immediate family cared for her in her home without any assistance from outside sources. I often wondered why they didn't reach out for help - was it embarrassment, pride, or lack of knowledge? The caregiver finally agreed to place her in long term care as he was wearing out. It was such a strain on the family but they also did not accept any suggestion of assistance. How do we approach this type of family to offer help?

I would like to attend a day long workshop in the Estevan area. I believe it would be beneficial for staff and families.

I have had very little training in Alzheimer's and other dementias but am interested to learn more.

Identifying a champion or 2 in each community who could be further trained might assist with furthering the cause.

Please do watch W5 in Deadly Care and listen carefully to Sue Ellen of Saskatoon's Sherbrooke Place. They are making the right decisions for the Dementia Patients. We all can learn from what they already know.

Need more advertising for family and staff when educational programs are available and for more services.

I'm enjoying my work here. I am only half time, so there is little time during the week to be involved in educational opportunities, as I feel work should come first. I would be open to working additional days if it was an educational opportunity and was recognized as a workday.

I feel there is a huge need for continuing education in our health region, on dementias and have it offered in our locality, instead of travelling to Weyburn.

We feel there is a need for more continuing care education in our region on dementia and Alzheimer's.

Summary

The majority of Continuing Care Aides (CCAs) and Home Care Nurses, Case Managers, and Home Care Nurse/Case Managers (HCN/CMs) estimated that more than 30% of their patients had dementia due to AD or another cause.

The majority of CCAs (66%) compared with 18% of HCN/CMs reported that their community has adequate support services for persons with AD or other dementias.

Three main issues emerged from respondents' comments regarding the impact of inadequate community services: *Patient issues* included late disease detection, increased travel to access services, lower quality of life, increased safety risks, risk for earlier institutionalization, and possible loss of relationships due to relocation. *Family issues* included lack of education, poor coping abilities, increased stress, health problems, and risk for burnout mainly due to lack of respite services. *Staff issues* included fewer education opportunities, greater isolation, lower quality of life, and increased workload and risk of burnout.

Three of the five most frequently reported regular work activities were the same activities among both HCN/CMs and CCA groups: 'assessing risk for falls', 'recognizing changes in patients' cognitive function', 'with patients/families, discussing safety issues'.

Nearly half of HCN/CMs (49% and over) perceived their competency to be at the novice/beginner level with respect to five of 20 work activities related to AD and other dementias: 'recognizing differences between dementia subtypes', 'with patients/families, discussing legal issues', 'assisting with daily living activities', and 'with patients/families, discussing anticipated changes as the disease progresses', and 'detecting early symptoms of ADRD'. Among CCAs, perceived novice/beginner competency levels were most frequent (51% and over) with regard to 12 of 20 work activities related to AD and other dementias, including: 'with patients/families, discussing legal issues', 'recognizing differences between dementia subtypes', and 'evaluating cognitive status with a standardized cognitive test'.

The education topics ranked in the top 5 among HCN/CMs were 'recognizing differences between dementia subtypes' (Rank 1, 76%), 'with patients/families, discussing anticipated changes as the disease progresses', 'detecting early symptoms of AD and other dementias' (Rank 2, 54%), 'with families, discussing strategies to manage behavioural symptoms in patients' (Rank 3, 39%), 'evaluating cognitive status with a standardized cognitive test', 'with patients/families, discussing legal issues', 'with families, discussing strategies for effectively communicating with patients' (Rank 4, 37%), and 'managing behavioural symptoms in patients' (Rank 5, 34%). The topics ranked in CCAs' top 5 were 'recognizing differences between dementia subtypes (Rank 1, 66%), 'detecting early symptoms of AD and other dementias' (Rank 2, 54%), 'recognizing changes in patients' cognitive function' (Rank 3, 39%), 'assessing functional ability in patients', 'providing palliative care for

patients' (Rank 4, 37%), and 'managing behavioural symptoms in patients', 'with patients/families, discussing anticipated changes as the disease progresses' (Rank 5, 34%).

The top-ranked barriers to attending a Continuing Education (CE) program on any topic among HCN/CMs were 'low staffing levels' and 'geographically difficult to access' CE programs. 'Low staffing levels' also ranked first among CCAs.

Locally offered CE programs and paid time off to attend CE programs were the two primary enablers suggested by Home Care staff. Secondary enablers included improved advertising of CE opportunities, adequate staffing to allow a group of staff to attend CE programs together, offering CE via Telehealth, and awarding certificates for CE program participation. Secondary enablers also included employer action on ideas that emerge from staff as a result of CE participation, financial support from employers, and managers making CE program arrangements for staff.

About RaDAR

The Rural Dementia Action Research (RaDAR) Team is an interdisciplinary group of researchers from Ontario, Alberta, and the United Kingdom, based at the University of Saskatchewan. Dr. Debra Morgan, Professor in the Canadian Centre for Health and Safety in Agriculture, College of Medicine, leads the RaDAR Team.

Since 2003, the RaDAR Team has been working together to improve rural and remote dementia care and is a founding member of the Gateway to Rural International Initiatives in Dementia (GRIID). RaDAR's flagship project is the Rural and Remote Memory Clinic, a SK Ministry of Health funded clinic which focuses on diagnosing and managing atypical and complex cases of suspected dementia in patients living in rural and remote communities outside of Saskatoon and Regina.

The RaDAR Decision-Maker Advisory Council provides guidance to the team, and meets annually at the Summit of the Knowledge Network in Rural and Remote Dementia Care. The Council includes health care providers, family members, health region representatives, and governmental and community-based organizations. The next Summit is the 7th annual and will be held October 21-22, 2014 in Saskatoon.

To learn more about the research and activities of the RaDAR Team, visit their rural dementia care website: www.cchsa-ccssma.usask.ca/ruraldementiacare. To learn more about GRIID, visit www.ruraldementia.com.



Dr. Debra Morgan



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