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Championing Dementia Education: Adapting an Effective Scottish Dementia Education

Programme for Canadian Acute Health Care Providers

~ Accepted manuscript ~

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Abstract

With increasing numbers of persons living with dementia and their higher rates of hospitalizations, it is necessary to ensure they receive appropriate and effective acute care; yet, acute care environments are often harmful for persons with dementia. There is a lack of dementia education for acute healthcare providers in Canada. Scotland presently delivers a dementia education programme for healthcare providers, known as the *Scottish National Dementia Champions Programme*. The objective of this *Policy and Practice Note* is to present the collaborative work of Scottish experts and Canadian stakeholders to adapt the Dementia Champions Programme for use in Canada. This work to date includes: (a) an environmental scan of Canadian dementia education for acute healthcare providers; (b) key informant interviews; and, (c) findings from a two-day planning meeting. The results of this collaborative work can and are being used to inform the next steps to develop and pilot a Canadian dementia education programme.

Championing Dementia Education: Adapting an Effective Scottish Dementia Education

Programme for Canadian Acute Health Care Providers

In Canada, approximately 7% of older persons over the age of 65 years have some form of dementia, with around 76,000 new cases diagnosed each year (Public Health Agency of Canada, 2017). Older persons with dementia have twice as many comorbid conditions as those without dementia and are at increased risk for other health issues including falls, infections, and stroke (Poblador-Plou et al., 2014; World Health Organization, 2019). Indeed, research has shown that persons with dementia are more likely than those without to be admitted for emergency hospitalization (Canadian Institute of Health Information, 2018; LaMantia, Stump, Messina, Miller, & Callahan, 2016; Sommerlad et al., 2019). With increasing numbers of persons living with dementia and higher rates of hospitalization, it is necessary to ensure they receive appropriate and effective acute care. In this *Policy and Practice Note* we present our internationally collaborative work to bring a dementia education programme for acute healthcare providers (HCPs) to Canada. Herein we present: (a) an overview of the programme; (b) results from a national environmental scan; (c) key informant interviews; and, (d) findings from a two-day meeting to begin initial work towards adaptation.

Research suggests that acute care environments are often harmful for persons with dementia (Dewing & Dijk, 2016). Commonly identified issues include: lack of privacy, noise, overcrowding, loss of independence, difficulty wayfinding, boredom and lack of meaningful activities, unmet needs, and bed/ward moves (Clissett, Porock, Harwood, & Gladman, 2013; Digby & Bloomer, 2014; Hung et al., 2017; Jurgens, Clissett, Gladman, & Harwood, 2012; Moyle, Bramble, Bauer, Smyth, & Beattie, 2016; Parke et al., 2017; Prato, Lindley, Boyles, Robinson, & Abley, 2019). Persons with dementia may also feel devalued and disempowered when acute HCPs do not include them in conversations or respect their wishes for care (Hung et al., 2017). Families also report unmet expectations regarding personalized care and the maintenance of their relative's dignity, physical comfort, privacy, identity, and safety (Jurgens et al., 2012). Acute HCPs often appear focused on medical treatment and task-oriented care, while not necessarily meeting the person's fundamental care and broader psychosocial needs (Jurgens et al., 2012; Moyle et al., 2016). In addition to the wellbeing of the person with dementia, families have identified communication with acute HCPs as a major issue (Jurgens et al., 2012; Moyle et al., 2016).

Acute HCPs describe many of the same issues, recognizing and aiming to minimize the disorientation persons with dementia often experience, acute HCPs work to create a safe environment, establish positive relationships, and attempt to initiate activity routines (Hynninen, Saarnio, & Isola, 2014; Pinkert et al., 2018). Prato et al. (2019) reported that acute HCPs felt it was important to practice person-centred care and empower persons with dementia, yet this did not always occur.

The busy pace of wards and understaffing affect the amount of time acute HCPs can spend interacting with persons with dementia, who are perceived to require more time and effort for care than other persons (Coffey et al., 2014; Houghton, Murphy, Brooker, & Casey, 2016; Hynninen et al., 2014; Pinkert et al., 2018). Acute HCPs also report inadequate dementia care training, resulting in reduced confidence and capability to effectively care for persons with dementia (Dewing & Djik, 2016; Cowell, 2010; Coffey et al., 2014; Hynninen et al., 2014; Pinkert et al., 2018).

Given these concerns, there have been calls for enhanced dementia education and development of standards and core competencies for acute HCPs (Canadian Academy of Health

Sciences, 2019; Houghton et al., 2016; Hynninen et al., 2014). Indeed, improving dementia care is an identified priority for Canada (Alzheimer Society of Canada, 2019) and is reinforced by Canada's National Dementia Strategy principles (Public Health Agency of Canada, 2019). Moreover, there is a clear need for efforts to go beyond educating individuals and enable positive changes at unit, department, and organizational levels (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010; Pinkert et al., 2018).

Acute HCPs have access to few effective dementia education programs (Gkioka et al., 2020). One program in Canada described acute care staff's experience with Gentle Persuasive Approaches (GPA), a program developed for long-term care staff to improve hands-on dementia care (Gkioka et al., 2020; Hung et al. 2019). GPA was evaluated in an acute care hospital in Ontario and had a positive effect on staff self-efficacy; however, impact on patient health was not assessed (Martin et al., 2016). While important, the GPA program does not involve the sufficient training intensity that Gkioka et al. (2020) suggest is necessary to make changes at the organizational level in culture and practice within acute care settings. Moreover, the GPA was not designed for acute care settings. To the best of our knowledge, no extensive dementia education programme specifically for acute HCPs exists in Canada, despite the need for such a programme.

A dementia education programme designed specifically for acute HCPs that has evidence for effectiveness is delivered in Scotland. The *Scottish National Dementia Champions Programme* (herein referred to as the Programme) equips acute HCPs with the knowledge, values, and skills needed to provide high-quality dementia care and support them to lead change in their care areas (Banks et al., 2014). Evaluation has shown that the Programme has a measurable impact on participants' knowledge of dementia, approaches to care and confidence in their ability to achieve the Programme's learning outcomes (Jack-Waugh et al., 2018). A Mental Welfare Commission for Scotland report (2018) highlighted the clear benefits of additional access to resources for other staff, persons with dementia, and carers. The Programme was developed to provide enhanced education that considers the complex systems that exist in the acute care context. Surr et al.'s (2017) systematic review identified several criteria of effective dementia education (e.g., relevant to participants' role, encompasses in-person participation, taught by an experienced facilitator, has greater than 8 hours of sessions, etc.); the Programme includes all of them. Given its rigorous development and focus on both individual education and broader practice/organizational change, the Programme could potentially address dementia education gaps for acute HCPs in Canada.

The Programme was commissioned as part of Scotland's first dementia strategy, in response to the poor acute care persons with dementia were experiencing (Alzhiemer's Society, 2009; Elvish et al., 2018; The Royal College of Psychiatrists, 2011). Funded by the Scottish Government in collaboration with the National Health Service Education for Scotland, and the Scottish Social Services Council, the Programme has been running since 2011. The University of the West of Scotland led the design and delivery of the Programme in partnership with Alzheimer Scotland. The Programme's underlying pedagogical approach is described by Jack-Waugh et al. (2018) and illustrated in Figure 1. Human rights, values-based care, and an understanding of the social model of disability (Durrell, 2014) form the Programme's theoretical spine (Jack-Waugh et al., 2018). Its pedagogy is informed by transformative learning theory, working with the affective (heart), cognitive (head), and psychomotor (hands) domains (Singleton, 2015). A collaborative approach to delivery has been central to enacting the Programme's ethos; persons with dementia, family carers and health and social care practitioners are all part of the education team. The Programme is grounded in Kitwood's (1997) theoretical perspective of person-centred care for persons with dementia. The principles of valuing persons with dementia and their carers, treating them as individuals, seeing the world from the person with dementia's perspective, and creating a positive social environment that promotes their wellbeing (Brooker, 2003) are all foundational to the Programme's goals and teachings.

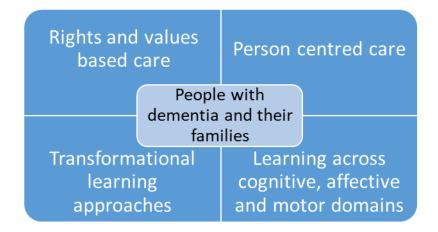


Figure 1 Pedagogy of the Dementia Champions Programme

(Source: Jack-Waugh et al., 2018)

The Programme's main objective is to provide enhanced dementia care education to HCPs, supporting them to lead change in acute care settings that will improve care for persons with dementia and their families. The six-month Programme includes: a blended educational program with pre and post reading for the five in-person study days and half-day community placement; three written assignments; and development of a collaborative change plan to improve dementia care in their care setting. In sum, the Programme's unique elements include: (a) recognizing the challenges in acute care settings; (b) using a rights-based approach; (c) having persons living with dementia as an integral part of the teaching team; (d) partnering with family carers, and (e) disseminating the champions' developed activities to benefit their colleagues. The Programme's learning outcomes and topics covered in the teaching sessions are

listed in Tables 1 and 2 respectively.

Table 1 Dementia Champions Programme Learning Outcomes

People who have completed the Dementia Champions education programme will be able to, in accordance with their job description, roles and responsibilities:

1. Understand, recognize and respond to the impact of the physical, emotional, social, cultural and spiritual environment on the maintenance of rights, choice, identity, dignity, participation and equity for the person with dementia in acute hospital settings.

2. Understand, identify and respond with evidence informed best practice, to the physical and mental health issues that may affect the individual course of a person's journey before, during and after receiving care in the acute hospital environment.

3. Understand and identify the complexities associated with dementia in the acute hospital setting that may have legal and ethical implications and act to safeguard the best interests of people with dementia, families and carers.

4. Understand, apply and evaluate a range of approaches to reduce stress and distress and promote ability, strengths and quality of life for the person with dementia, paying particular attention to demonstrating kindness, empathy, enablement, partnership working and compassion.

5. Understand and implement leadership and change agent skills and knowledge to enhance and improve the care of the person with dementia in every area of their influence, utilizing existing and developing quality improvement systems, sharing good practice forums and knowledge networks.

(Source Banks et al., 2014)

Day	Morning Session	Afternoon Session				
One	Welcome	Expectations of Programme				
	Hearing the voice of people living					
	with dementia					
Two	Assessment and identification of	The dementia journey: Person-centred				
	wellbeing and illbeing	planning, support and risk enablement				
Three	Working with stressed and	Care Empathia				
	distressed behaviour					
Four	Palliative approaches	Work as equal partners with families,				
		friends, and carers				
Five	Moving on as a Dementia Champion	Expert master classes (legal issues,				
		supportive technologies, and Introduction to				
		Positive Approach to Care)				
		End day with Musical Minds performance				
	Graduation and Celebration					

 Table 2 Scottish Programme Sessions

(Source Banks et al., 2014)

To date, over 1,000 qualified health and social care professionals have completed the Programme in Scotland. Approximately 70% of participants are qualified nurses; other participants include: allied health professionals (e.g., occupational therapists, physiotherapists, speech and language therapists, podiatrists, dietitians), nurse educators, managers (discharge and patient flow), and hospital social workers. There is evidence that some champions have made demonstrable practice improvement such as: implementing 'Getting to Know Me' (Alzheimer Scotland, 2015) to provide more person-centred care, improving pharmaceutical support, environmental design and change, increased partnership with families, delirium prevention, personal music, a bedside vascular service, creation of quiet spaces and gardens, activity boxes, and dementia cafés (Jack-Waugh et al., 2018). Developing examples of some of the Dementia Champions' actions can be accessed through #oneweething and the Blog: https://letstalkaboutdementia.wordpress.com/.

Adapting the Programme for Canada

Providing comprehensive dementia care education to acute HCPs will increase their capacity to provide optimal care to persons with dementia, which is one of the priorities identified in Canada's National Dementia Strategy (Public Health Agency of Canada, 2019). The Programme's focus on individual dementia care education together with broader practice and system change is unique. This programme was chosen for adaptation in Canada because of these foci, its grounding in best practices, its success in Scotland, and the generosity of our Scottish colleagues in sharing their knowledge throughout the adaptation process. The fit between the Programme and philosophical goals of dementia care in Canada, specifically the strong grounding in person-centered care and inclusion of persons with dementia and carers as peer educators (Jack-Waugh, 2018) is also fundamentally important. Co-production is embedded within our work via Hawkins and colleagues' (2017) framework for the co-production of an intervention entailing three stages: 1) evidence review and stakeholder consultation; 2) co-production of intervention content; and 3) prototyping the new intervention. This *Policy and Practice Note* presents the first stage of evidence review and stakeholder consultation, which included three steps: (a) an environmental scan to examine existing dementia education for Canadian acute HCPs; (b) key informant interviews with two carers and one person with dementia about their experiences of acute care and issues needing attention, to hear from those with recent lived experience; and (c) a planning meeting with various experts—including our Scottish collaborators (AJW and RM)—to establish programme principles, priorities, learning outcomes, pedagogical approaches, and content for a Canadian programme. These steps (along with a literature review) constitute evidence review and stakeholder consultation, laying the groundwork for co-producing intervention content. The process and outcomes of each step are described below. Ethical approval for each step was received from the Research Ethics Board of the University of Saskatchewan.

Adaptation Activities and Findings

Environmental Scan of Current Canadian Programming

The purpose of the environmental scan was to examine the literature and publicly available information (Graham, Evitts, & Thomas-MacLean, 2008) guided by the work of Choo (1999) to identify currently available Canadian dementia education programmes for acute HCPs. Strengths, limitations, and gaps of the programmes were also considered.

Methods. Data for the environmental scan (Choo, 1999; Graham et al., 2008) included correspondence (n=4 telephone interviews, n=4 email communications) with Alzheimer Society staff from across Canada between November 2019 and February 2020. Since most dementia

education occurs either directly or in partnership with Provincial/Territorial Alzheimer Societies, they were considered the key experts to consult. Alzheimer Society offices were contacted by email, and participating staff were asked to provide their perspectives on challenges/needs faced by persons with dementia when in acute care. They were also asked to identify any existing dementia education programmes for Canadian acute HCPs offered by their organization or others, and describe what they thought would be essential to include in such a programme. Data from the staff was transcribed and analyzed for salient content using a thematic analysis approach (Braun & Clarke, 2006). Other data on existing programming was obtained via a Google search conducted between September 2019 and January 2020, using the terms "Canada", "dementia education", "workshops", and/or "online/webinar".

Findings. The environmental scan's findings include: (a) challenges, needs, and priorities of persons with dementia in acute care shared by Alzheimer Society staff; and (b) current education programmes for acute HCPs on offer in Canada as identified by staff and the Google search, and components/elements that should be included in an education program for acute HCPs (Surr et al., 2017).

Challenges, needs, and priorities of persons with dementia in acute care. Alzheimer Society staff perceived persons with dementia and their carers as facing stigma, disabling built environments, limited HCP understanding and knowledge of dementia, and a lack of personcentred care. Staff felt persons with dementia were misunderstood by acute HCPs, "who often have stereotypic and stigmatized images in their heads of what a person with dementia looks like" (telephone interview). By identifying as a person with dementia, a person may be ignored or communicated to differently, and unrelated symptoms may be assumed to be "just dementia, this is nothing more" (telephone interview). Staff also felt that persons with dementia and their carers may not disclose a dementia diagnosis to acute HCPs to avoid misdiagnosis and mismanagement of illness or pain.

Staff-cited gaps in acute HCPs' dementia-related knowledge included: lack of systematic protocols for supporting persons with dementia in acute care, absence of training to identify persons with dementia and their symptoms, lack of clarity around effective communication with persons with dementia, and inappropriate use of physical and chemical restraints. For example, staff shared stories such as HCPs "using straps to tie [a person] to the bed, which is very alarming to see a family member tied down like that, and of course resorting to medications to calm [a person with dementia] down" (telephone interview) instead of trying to determine and address their needs. A lack of person-centred approaches to care, with the predominance of a general *one size fits all* approach, insufficient continuity of care, and inadequate communication between acute HCPs and families were identified. The challenges and unmet needs staff identified are consistent with the reviewed literature, suggesting these issues remain in Canadian acute care environments.

Staff identified elements of acute care that could be improved to address the above issues. They emphasized that care should be provided by HCPs who have received enhanced experiential simulated learning of dementia, because persons with dementia "should be cared for by a team who has received the proper education/training" (email communication). They stressed the need for acute HCPs to be educated about dementia (e.g., types, diagnosis, treatments, and symptoms). Staff felt that acute HCPs should know how to: (a) support persons with dementia; (b) provide person-centred care; (c) connect families with dementia support services; (d) work in partnership with families/carers; and (e) improve communication about the person's needs, likes, and abilities. Staff also felt that preparing persons with dementia and carers for acute care could be helpful. For example, carers could create a written summary with the person with dementia about their most critical healthcare needs, current abilities, and dis/likes, that could be brought into acute care and shared with HCPs. Staff identified the Alzheimer Society's *First Link* as another resource that could help to prepare families for acute care settings (McAiney, Hillier, Stolee, Harvey, & Michael, 2012).

Lastly, staff felt built environments should be modified to be more enabling and dementia-friendly. Acute care environments by design are clinical spaces, often very bright with shiny hard surfaces, noisy and difficult to navigate. Without adaptations for persons with dementia, environments can be both distressing and disabling. Staff identified several potential modifications, including clear wayfinding signage, lighting to improve visibility and reduce glare, access to quiet spaces/rooms, consistent use of visible staff name tags, and standard uniforms "that make staff recognizable" (telephone interview). Overall, staff felt that improving acute care experiences for persons with dementia and their carers would require a significant culture shift within organizations.

Current education programmes for acute HCPs. We identified sixteen educational programmes in Canada that incorporate dementia education accessible to acute HCPs. Table 3 describes the location, audience, curricula, accessibility, and cost of these programmes. Dementia care was the specific focus of six programmes, although all included a dementia-related component. The other programs focused more broadly on persons living with dementia, psychiatric and cognitive disorders; those in palliative care; and older persons in general. The target audience of most programmes was HCPs working in a range of settings; no programme was specifically focused on acute HCPs. Six programme websites did not provide specific information about dementia-related curricula and four programmes could only be accessed

online. Of the seven programme websites that included curricula, commonly covered topics were screening, diagnosis, communication, and brain and behaviour changes. Less often, curricula included topics such as self-protection strategies for HCPs, strategies for risk situations, action planning, and general information on aging. Some of the components of effective dementia education (Surr et al., 2017) were clearly part of identified programmes: 10/16 programmes offered face-to-face courses (three did not specify), 10 included course options that had a total duration of 8 hours (three did not specify), six provided individuals with a structured tool (10 did not specify), six included interactive learning (seven did not specify), five were delivered by an experienced facilitator (10 did not specify), four supported the application of learning in practice (six did not specify), and one noted programmes were oriented to be relevant to the learner (15 did not specify).

<Table 3 Canadian Resources>

Findings from this environmental scan suggest that dementia education for Canadian acute HCPs is limited and piece-meal across the country, and not geared specifically toward acute care. Moreover, while some programmes are grounded in concepts of person-centred care and include a focus on understanding the person with dementia and their needs, none address the concern that education of learners should tackle broader shifts in practices, policies, and organizational cultures within acute care (Moyle et al., 2010; Pinkert et al., 2018). This illustrates the need for a Canadian programme that supports acute HCPs to both increase their knowledge of dementia, and lead and implement change on a broader scale (Surr et al., 2017).

Lived Experience Interviews

The purpose of the key informant interviews was to provide a means for planning meeting participants to hear the experiences of persons with dementia and carers, and identify

any additional issues that may be unique and important to address in the Canadian dementia education programme for acute HCPs.

Methods. Semi-structured face-to-face interviews were conducted with three key informants (one man living with dementia and his wife carer, and an additional woman carer) recruited through the Alzheimer Society of Saskatchewan, who had experienced an acute care admission within the last 12 months. Given the purpose of our key informant interviews was to hear about recent acute care experiences (not to provide information about acute care experiences that is generalizable to all persons with dementia and carers), the small number of participants was deemed sufficient. Informants were asked questions like: (a) Can you please describe your recent experience in the hospital? (b) What do you think needs to change to better support people with dementia and family carers who are accessing hospital care? And (c) What is most important for healthcare providers working in hospitals to know about what it is like to be a person with dementia or a family carer of a person with dementia going to the hospital for care? Interviews were held in informants' homes and were audio-recorded then transcribed. Thematic analysis (Braun & Clarke, 2006) was conducted to identify key elements of informants' experiences. Analysis involved an iterative process (undertaken by SP and KH), whereby transcripts were read and re-read for key aspects of the informants' experiences; then coding was performed to capture key elements in the data; developing and refining themes in collaboration with AJW to highlight the salient elements of the informants' experiences.

Findings. Key informants highlighted the importance of three things: the need for frequent and effective communication from acute HCPs, the nature of acute care environments, and the need for person- and family-centred care. First, informants spoke at length about the significance of regular contact with and communication from providers. A communication

vacuum was the biggest problem in their acute care experiences; they described missed opportunities to connect with doctors and lack of sufficient communication from nurses:

I never met the doctor that was supposed to be looking after him. The nurses wouldn't tell me a lot. I wasn't happy with it, but he was being looked after and that was the most important thing to me... I just thought there was a lack of communication. I'd want some information and I didn't get it. 'He's doing fine' or something like that. I wanted to know exactly (Carer #1).

Carers desired clear communication about how the person was doing when they were not there, medical information from supervising doctors, and chart updates. They wanted this communication on a regular and ongoing basis and did not want to have to "chase down" acute HCPs to get it; an often unsuccessful endeavour. Communication was considered crucial because the symptoms of dementia made it difficult for the person to remember and effectively communicate details to their carers.

It was also important that communication be concrete, effective, and accessible. For example, our informant with dementia identified the value of having printed information to supplement verbal communication: "Actually giving documents or a note of something, saying this is what we have discussed. So it doesn't just go in one ear and out the other, because I have a hard time retaining things sometimes." One carer noted that she also appreciated when acute HCPs were patient with her loved ones when they did not understand or forgot information.

Secondly, the acute care experience was improved when the setting was "homey" and had windows so the person with dementia could look outside. Crowded, dingy, and depressing environments were problematic, as were lighting and noise: I find that I need the calm and you're in a ward with a whole bunch of other people...

You're just having a nap and more visitors come in. That really gets me going. It's a hectic environment to be in... I find it stressful (Person with dementia).

One carer suggested that not having a quiet space, sharing a room with other patients, and disrupted sleep exacerbate emotions like anxiety, agitation, fear, and uncertainty that persons with dementia may experience in acute care. She suggested this should be mitigated by more attention to the allocation of persons with dementia to particular spaces, and a more personalized approach to care.

Finally, it was clear that a person- and family-centred approach to care was important. Informants appreciated opportunities for personal connection with acute HCPs wherein they felt valued: "That really does go a long way when you're seeing the same people, and they know you, and you have the sense that they know you... I think connection is really, really important" (Carer #2). Feeling a connection was closely tied to communication and not feeling like information was withheld, as well as interactions where HCPs were patient, kind, and understanding. It was important to carers to be involved in the care of the person with dementia via communication with acute HCPs, so that care was family-centred. Although informants were satisfied with the medical care persons with dementia received, one of the carers was distressed by instances where her husband's fundamental needs and human rights were not met: "He used to say he had to go to the bathroom, they'd say 'well he has to wait until one o'clock, he can't go because it takes two of us to sit him in the bathroom', I always found that hard" (Carer #1). Other issues were the need for comfort in the acute care environment, stability (not being repeatedly moved to different environments), and support maintaining mobility. The experiences of informants were consistent with the broader literature (e.g., Clisset et al., 2013; Hung et al., 2017; Jurgens et al., 2012; Moyle et al., 2016). In particular, the importance of regular and appropriate communication that is not only effective in conveying information but also engenders a person- and family-centred approach was highlighted. Hearing informants' experiences reaffirm these critical aspects for education and practice change.

Planning Meeting

The purpose of the planning meeting, held over two days in February 2020, was to bring experts (n = 19, academics from across Canada, community stakeholders from the Alzheimer Society of Saskatchewan and older adult community services, acute care clinicians such as nurses and a psychologist, and a couple living with dementia) together to collaborate on how to adapt the Dementia Champions Programme to the Canadian context. Those who could not attend in-person (n = 3) participated via WebEx. The objectives were to: (a) establish Canadian priorities for dementia education; and (b) use these priorities to adapt the overarching learning outcomes and individual sessions of the Programme. SP, AJW and RM collated pre-meeting information to share with the participants, included a summary of the environmental scan described above, the executive summary of Canada's National Dementia Strategy, and a summary of the Programme objectives. Detailed agendas were created for each day to guide and inform the meeting process.

Day one. Priorities for acute HCP dementia education in Canada were established using an adapted Nominal Technique (American Society for Quality, 2019). First, participants watched a video created (by KH and SH) that shared our key informants' experiences in acute care. This was important to ensure their experiences and issues were foreground in discussions of priorities, and to reflect the importance of involving persons with dementia and carers as peer-educators. The group then deliberated and voted on main priorities. Participants were asked "In light of your dementia research, education, and/or practice experience, if you were to design a dementia education programme for professional healthcare staff working in acute care settings what would your top three priorities need to include?" Participants wrote their priorities on sticky notes and added them to a blank wall chart for the group to view (those participating by Webex emailed their priorities to be added). Priorities were thematically grouped on the wall chart by two collaborators (SP and AJW). Participants discussed these themed priorities then voted (via sticky notes) for the three they believed were most important. Voting and subsequent discussion showed that participants felt a person- and family-centred approach was crucial as a philosophy for care, and should ground all other priorities: (a) communicating effectively; (b) working with responsive behaviours; (c) understanding different dementias; (d) creating supportive environments; and (e) identifying leadership qualities that lead to advocacy (Figure 2 captures this process of establishing these priorities).



Figure 2 Canadian Priorities

Once Canadian priorities were drafted we heard from WD about how to effectively adapt interventions; this was important so the group recognized the need to maintain the fidelity of the Programme while reflecting the principles of Canada's National Dementia Strategy, healthcare system, professional education, and values. We continued with a presentation on the Programme's five overarching learning outcomes (AJW). We then used an adapted World Café (The World Café, 2020) approach to adapt the outcomes to a Canadian context, bearing in mind the identified Canadian priorities. Five flipcharts, each listing individual outcomes were placed on 5 tables. Participants moved about the room (in 5 minute intervals) between the flipcharts to discuss written feedback on adapting the Scottish learning outcomes. The adapted outcomes for Canada can be viewed in Table 4. The Canadian learning outcomes incorporate differing action words (e.g., instead of "understand and identify" we used "promote" for learning outcome #3), yet align with Scottish learning outcomes as our identified priorities were largely reflected in the Scottish programme. We refined the learning outcomes and incorporated language common to Canada (e.g., learning outcome #4 'responsive behaviours'). The day ended with a participatory example of simulated experiential learning of one pedagogical approach used in the Programme lead by RM. These activities sensitized participants to the work ahead in adapting the Programme's individual sessions.

Table 4 Canadian Programme Learning Outcomes

People who have completed the Dementia Champions education programme will be able to, in accordance with their job description, roles and responsibilities:

1. Recognize and respond to the impact of the physical, emotional, social, cultural and spiritual aspects to maintain, rights, choice, identity, dignity, participation, and equity for the person with dementia in acute care settings.

2. Understand, anticipate, and respond with evidence informed best practice, to the biopsychosocial needs that may affect a person living with dementia before, during, and after receiving care in an acute care setting.

3. Promote the legal and ethical principles in all aspects of care for persons living with dementia, their families, and carers.

4. Understand and respond to responsive behaviours and promote quality of life of persons living with dementia.

5. Implement leadership, knowledge, and change agent approaches to improve the care of persons living with dementia.

Day two. We began with a detailed overview of the Programme (presented by RM) and moved onto the individual programme sessions. Participants worked in small groups to consider the content of each session (two per day, for five days) that makes up the programme. We displayed the Canadian priorities identified the day before to guide participants in co-producing *what* needs to stay in the session, *how* the session can be taught, and *who* is best skilled at delivering the content. Each table had significant feedback that was recorded by facilitators (student research assistants). Written documents capturing this feedback have been retained and will be used to develop specific content for the Canadian programme.

After summarizing the work from the morning, the final afternoon concluded with a session to strategize future directions. This included identification of a knowledge dissemination plan for our work to date, and discussion of funding opportunities to support the continued development and pilot of the Canadian programme. As part of knowledge dissemination, we took the opportunity to record comments from our expert participants to develop a video and lay summary of the planning meetings (Bayly, Peacock, Jack-Waugh, & MacRae, 2020).

Summary and Next Steps

Our overall aim is to co-produce a dementia education programme that embodies Canadian healthcare values, principles, and priorities for dementia care in acute care settings, and has utility and acceptability for those providing and receiving care. The work described within this *Policy and Practice Note* reflects the first stage of the co-production of an intervention (evidence review and stakeholder consultation; Hawkins et al., 2017), including an environmental scan of existing Canadian dementia education programmes available to acute HCPs, key informant interviews, and a planning meeting event bringing together experts from Scotland with Canadian stakeholders. During the planning meeting, participants identified Canadian priorities for dementia education, overall learning objectives for a Canadian programme, and provided feedback related to each session of the Programme. Including only three key informants with lived experience of dementia in our interviews could be viewed as a limitation, but their rich accounts of their acute care experiences were useful to inform the work in the planning meeting. Additionally, we could have interviewed acute care providers prior to the planning meeting to gain their perspectives on challenges and gaps regarding dementia education; their perspectives will be highlighted via focus groups as we refine the programme for implementation. Access to detailed information about the various dementia education programmes in Canada was limited to the knowledge of Provincial/Territorial Alzheimer Society staff and what is publicly accessible; regardless, no dementia programmes in Canada exist that are comparable to the Programme. Our work from the planning meeting is significant to moving forward with a Canadian programme.

The results of this planning meeting are now being used to inform the next stage of coproduction, which is the co-development of the content (Hawkins et al., 2017) of the Canadian dementia education programme for acute HCPs. Once the core development group (SP, MB, RM, AJW, KH, LH, JB, and NR) creates an initial programme and implementation plan, these will be shared with key stakeholder groups for additional input. Of importance is to explore offering on-line/virtual options for programme delivery, given the vastness of Canada as well as the issues the COVID-19 pandemic revealed. We will hold two focus groups with persons living with dementia and their carers, as well as a focus group with frontline acute HCPs to ensure the utility and acceptability of the Canadian programme. Future research endeavours (that reflect the third stage of co-production) include acquiring funding to pilot and evaluate the Canadian programme. We will further develop and maintain our website (see

<u>https://www.dementiachampionscanada.com/</u>) to make our work visible and accessible to people who would benefit from a dementia education programme for acute HCPs.

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sheets/detail/dementia

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
Behavioral Symptoms https://www.amilia.co m/store/en/iugm/shop/ programs/37999	Behavioral Symptoms includes continuing education opportunities provided by the University Institute of Geriatrics of Montreal. Two courses were advertised in March, 2020 (Behavioral and Psychological Symptoms of Dementia and Behavioral, Psychiatric and Neurocognitive Disorders).	QC	Healthcare professionals	Online training series {program may no longer be available as of April 2021}	\$250 - \$300
Best Friends Approach ^{bcdfg} <u>https://bestfriends.heal</u> <u>thpropress.com/trainin</u> <u>g/introductory-</u> <u>training/</u> <u>https://bestfriends.heal</u> <u>thpropress.com/trainin</u> <u>g/advanced-training/</u> <u>https://bestfriends.heal</u> <u>thpropress.com/trainin</u> <u>g/master-trainer-</u> <u>certification/</u>	Introductory, advanced, and master trainer certification training options are offered by the Health Professions Press in the United States. The training involves a humanistic, relationship-based model to care for individuals living with Alzheimer's disease or dementia. In-person group training is led by an expert in the Best Friends Approach, and is offered as half-day, full day, or two- day training sessions.	Across Canada (American content)	Not specified	In-person group training sessions	\$1700-5500 (currency not specified)
Centre Montessori Alzheimer ^{bdf} <u>https://montessori-</u> <u>alzheimer.com/boutiq</u> <u>ue/fr/formations-c74/</u>	This intensive training in the Montessori Method adapted for older persons with dementia is offered over two days. It is intended for all professionals working with older people at home, in institutional and community settings, as well as caregivers.	French Canada	Healthcare professionals and/or caregivers	In-person workshops Training option 1 Training option 2	\$420 \$120 for virtual Zoom training \$1500 per group of 12 people for 2-

Table 3: Canadian Resources for Dementia Education

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
					day in-person training
Dementia Care Training ^{bcdefg} <u>https://alzheimer.ca/pe</u> <u>i/en/dct</u>	The Dementia Care Training program involves 2 two-day courses. The first course involves understanding dementia, U-First approaches, person-centred care, and more. The second course focuses on application of U-First principles, Montessori's DementiAbility methods, LGBTQ care guidelines, and more.	PEI	Healthcare professionals	In-person training program	\$300
Dementia Certificate Program ^{bde} <u>https://alz.to/courses- learning-</u> programs/dementia- certificate-program/	The Dementia Certificate Program includes two programs: Dementia care training (4 sessions) and behavioural support training (2 full days). Individuals become familiar with U-First approaches, person-centred care, management of responsive behaviours, and various other skills.	Toronto, ON	Healthcare professionals	In-person training program or online	\$150 in-person \$75 online
ECHO [®] Care for the Elderly- Dementia Series ^d https://baycrest.echoo ntario.ca https://baycrest.echoo ntario.ca/care-of-the- elderly/didactic- curriculum/winter- 2021-echo-care-of- the-elderly-dementia- series-curriculum/	The ECHO-dementia series is an educational resource via videoconference that covers one session topic per week for six weeks. Some topics include responsive behaviour, screening and assessment, and psychosocial care. Each session is led by a specialist in the specific topic area and includes patient cases.	Fall 2019 in ON	Primary healthcare providers	Online education curriculum	Free (funded by Ministry of Health and Long-Term Care)

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
The Emergency Management, Frailty, Dementia & Disasters e- Learning Program <u>https://brainxchange.c</u> <u>a/Public/Resource- Centre-Topics-A-to- Z/Emergency- management-frailty- dementia-and- disast.aspx</u>	The e-learning program contains 4 modules (emergency management, preparation, response, and recovery and mitigation) that take approximately 20 minutes each to complete. The modules are emergency- and disaster-related, and aim to inform individuals of the vulnerabilities persons with dementia may face in these situations and effective care for this population in an emergency.	Across Canada	Healthcare professionals , administrato rs, and policy makers	Online information modules {program may no longer be available as of April 2021}	Free
Gentle Persuasive Approaches (GPA) bcdefg https://ageinc.ca/gpaad p/gpa-certified- coach/gpa-certified- coach-training/ https://ageinc.s3.amaz onaws.com/uploads/20 20/12/IntegratedGPA- Flyer_IncludesVirtual Classroom_Nov2020. pdf https://s3.ca-central- 1.amazonaws.com/age inc/uploads /2018/03/AGE_Course Description_GPAeLE ARNING.pdf https://ageinc.s3.amaz onaws.com/uploads/	GPA Basics is a session lead by certified GPA coaches covering 4 education modules over a 7.5-hour day related to person- centered dementia care. The curriculum is provided by AGE Inc. (a not-for-profit organization for dementia education) and is offered as in-person sessions, online (incomplete), or through a combination of in- person and online material. GPA recharged is offered as a 2-hour review of the GPA Basics program.	Across Canada	Interdiscipli nary healthcare staff	In-person or online sessions	 \$21 in-person GPA basics \$6 in-person GPA recharged \$90 GPA eLearning \$32.50 - \$94.50 Integrated GPA (in- person and online) \$900 in-house coach delivery

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
2018/05/AGE_Course Description_GPABAS ICS.pdf					
Mieux intervenir, ca s'apprend ^d https://alzheimer.ca/en /federationquebecoise/ We-can- help/Programmes et services/Programme de formation professionnelle	A variety of course options are available within this Alzheimer's education program. These courses include a 30-hour course covering a person-centered care approach, 12-hour and 9-hour courses on daily help, a 6-hour course covering meaningful interactions, and a 15-hour course specifically for long-term care managers.	Training Education QC	Healthcare professionals	In-person courses {program may no longer be available as of April 2021}	\$10 per participant per hour
Pallium Canada LEAP Courses ^{bcdf} <u>https://www.pallium.c</u> <u>a/courses/</u> Leap Hospital: <u>https://www.pallium.c</u> <u>a/wp-</u> <u>content/uploads/2019/</u> <u>09/Pallium-LEAP-</u> <u>Hospital_one-</u> <u>pager.pdf</u>	Pallium Canada offers a variety of Learning Essential Approaches to Palliative Care (LEAP) courses in the form of interactive modules or in-person one day or two-day sessions. LEAP courses are not dementia focused; rather, they are broadly targeted towards palliative care. For example, LEAP hospital is an educational course for healthcare professionals concerning palliative care in hospital settings.	Across Canada	Healthcare professionals	In-person courses, online courses, or blended courses	Not Available
PIECES ^{TM d} http://pieceslearning.c om http://pieceslearning.c om/p-i-e-c-e-s- learning-development- program/ AB: http://pieceslearning.c om/alberta/ BC: http://pieceslearning.c om/british-columbia/	The PIECES TM learning and development programs address (P)hysical, (I)ntellectual, and (E)motional health, is centred on maximizing individuals' (C)apabilities, and considers patients' (E)nvironment and (S)ocial self. There are multiple in-person programs varying in length offered throughout Canada under the PIECES TM model. PIECES TM programs aim to improve the care of older individuals with complex	BC, AB, SK, MB, ON, NS	A variety of healthcare providers	In-person or online workshops	Not Available

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
MB: http://pieceslearning.c om/manitoba-2/ NS:	needs, including, but not limited to, people living with dementia.				
http://pieceslearning.c om/nova-scotia/ ON: : http://pieceslearning.c om/ontario/ SK:	Program delivered differently across provinces (e.g., 32 hours of content in MB versus 24 hours of content in NS).				
http://pieceslearning.c om/saskatchewan/					
Practice Support Program- Doctors of BC ^{abeg} https://gpscbc.ca/what -we-do/practice- supports/psp/learning- opportunities https://www.doctorsof bc.ca/managing-your- practice/quality- improvement/practice- support-program-psp	This program is targeted towards improving doctors' care approaches. "Learning Opportunities" are available to Doctors in B.C. in the form of in-person, online, or mixed sessions. Although the program is not focused on dementia, dementia management is one of the key learning topics.	BC	Doctors and their teams	In-person, online, or blended learning	Not Available
SafeCare BC - Various Dementia Workshops ^{bd} <u>https://www.safecareb</u> <u>c.ca/programs/worksh</u> <u>ops-events/</u> <u>https://www.safecareb</u> <u>c.ca/course-</u> <u>descriptions/</u>	Three types of workshops related to dementia are identified: Supporting persons with intellectual disabilities and dementia (pilot), Creating connections: Working with persons with dementia, GPA: Basics. A range of skills for dementia care is targeted, depending on the workshop. Workshops range from half-day to full-day time slots.	BC	Ranges from anyone to healthcare professionals	In-person workshops	\$35 (member), \$100 (non- member

Resource/website URL(s)	Description	Location	Audience	Accessibility	Cost in CAD
Supportive Pathways – Carewest ^{bfg} https://carewest.ca/de mentia-care-training/	Train the Trainer two-day sessions are offered every 2 months in the city of Calgary, Alberta, to individuals in healthcare management. Off-site group sessions are also available, and have been completed in British Columbia and Northwest Territories. The sessions are based on Supportive Pathways education, with the goal of enhancing quality of life for those living with dementia and encouraging family involvement.	AB	Healthcare educators, managers, and professionals	In-person sessions	Not Available
Teepa Snow's Positive Approach to Care: Becoming Dementia Aware ^c <u>https://teepasnow.com</u> /product/becoming- dementia-aware- online-course/	This online course is rooted in Teepa Snow's Positive Approach to Care (PAC). This course is accessible to anyone at any time through Teepa's website. The course curriculum consists of topics such as the brain, responding to changes, the positive physical approach, PAC skills, caring for all, and PAC team songs.	Across Canada (American content)	Open to anyone	Online training course	\$136 Online PAC course\$67 Online Champion courseFree Webinars
https://teepasnow.com /product/becoming- dementia-aware- online-course/ https://teepasnow.com /services/on-site- training/one-day- public-skills- champion-course/ https://teepasnow.com /services/online- learning/webinars/	Teepa Snow also offers free webinars on topics such as dementia care and care partner support. On-site training is also offered, but has currently transitioned to an online format to align with COVID-19 restrictions. Finally, an online PAC champions course covers the Positive Physical Approach, Hand-under- Hand, GEMS states, and GEMS state recognition.				

Resource/website	Description	Location	Audience	Accessibility	Cost in CAD
URL(s)					
U-First ^{bg} http://u-first.ca/about-	U-First aims to help frontline staff understand the behaviour of people living	SK, ON, PEI	Frontline staff	In-person or online	\$75 online
<u>u-first/</u> <u>http://u-</u> first.ca/training-	with dementia and form common knowledge, language, and values relating to the care process. The program is offered as a 3-week		involved with dementia	workshops	\$75 SK Free ON
registration/	online course or a 6-hour in-person workshop		care		Cost not
					available PEI

- a. Content relevant to participant's role
- b. Face-to-face instruction
- c. Experienced facilitator
- d. >8 hours of content
- e. Apply learning to practice
- f. Structured guide
- g. Interactive learning