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A Landscape for Training in Dementia Knowledge Translation (DKT)

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Meaningful translation of dementia research findings from the bench to the bedside is dependent on the quality of the knowledge to transfer and the availability and skills of investigators engaged in the knowledge translation process. Although there is no shortage of research on dementia, the latter has been more challenging. Results from a survey of 173 researchers from across Canada suggest that workshops and self-paced online training in dementia knowledge translation are needed to bridge the research-to-practice gap. Sharing information among professionals and with the public and formulating actionable messages to policy makers are primary goals.

KEYWORDS dementia, knowledge translation, knowledge transfer

INTRODUCTION

An estimated 35.6 million people have dementia today, representing a worldwide economic burden of more than \$600 billion (Wimo & Prince, 2010).

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In Canada, over the next generation, the prevalence of Alzheimer's disease is projected to increase from 1.5% to 2.8% of the population (Alzheimer Society of Canada, 2010b), and the annual economic burden is expected to increase 10-fold to a cost of more than \$150 billion (Alzheimer Society of Canada, 2010b). The associated investment in research on dementia is significant. In the United States, \$527 million was spent in 2010 alone on research directly related to Alzheimer's disease (National Institutes of Health, 2010). In Canada, \$22 million is spent annually on Alzheimer's disease research (Canadian Institutes of Health Research, 2010c).

Although all these numbers continue to rise, researchers, clinicians, and advocacy groups alike have identified a disconnection between new knowledge about dementia and the implementation of that knowledge for the benefit of patients (Alzheimer Society of Canada, 2010a; Janes, Sidani, Cott, & Rappolt, 2008; Rockwood, 2008). This is consistent with the observation of Graham and Tetroe (2007) who noted that the translation of research findings into clinical practice is often a slow and ambiguous process that spans multiple years and has variable results. Recent evidence from Germany suggests that as few as 20% of patients with dementia may be receiving care that is supported by current scientific evidence (Vollmar, Butzlaff, Lefering, & Rieger, 2007). Likewise, Gaddis, Greenwald, and Huckson (2007) reported that as much as 20% to 25% of care provided in the hospital setting may be unnecessary or even harmful to a patient. A report commissioned by the Alzheimer Society of Canada (2010b) similarly concluded that "while there is a broad spectrum of services appropriate to people with dementia and their caregivers at various stages of the disease, these services are maldistributed, uncoordinated and, where available, delivered with little standardization and continuity" (p. 14).

Dementia researchers come from many backgrounds: they are basic science experts, clinical evaluators, psychosocial investigators, among others. Although there remains no cure for the dementia syndromes, dissemination of the evidence-based knowledge to more effectively provide care for affected people is a shared need. Getting the right information out to the right people, in the right format, and at the right time is vital, yet effective pathways for this are still lacking. In the knowledge-to-action cycle (Graham & Tetroe, 2007), it is also incumbent upon researchers to ensure that information that emerges from end users such policy makers or caregivers is integrated into new research questions, dynamic and relevant.

Canadian researchers work with the following definition of knowledge translation (KT):

KT is the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research

for Canadians through improved health, more effective services and products, and a strengthened health care system. (Canadian Institutes of Health Research, 2008b)

Gone are the days when researchers could measure their academic success simply in terms of numbers of peer-reviewed publications and presentations at scientific meetings. Today, meeting KT objectives is imperative. Even grant applications to the federal government must explicitly address plans for KT. For the dementia field, this task is still new and daunting.

The Canadian Dementia Knowledge Translation Network (CDKTN) was developed to address these challenges. Lusk and Harris (2010) of the Network developed a framework for competencies in dementia knowledge translation (DKT). The competencies are a) understanding stakeholder goals and cultures, b) fostering collaborations between knowledge users and producers, c) translating evidence into policy and practice, and d) managing information and knowledge. Our team has further proposed that appreciating the unique features of DKT associated with changing definitions of dementia, the heterogeneity and dynamic changes in cognitive and decision-making capabilities of patients, and stigma and discrimination complete the key elements of a competency framework in the DKT domain (Chahal, Beattie, & Illes, 2010). As such, KT involves a reconceptualization of the research dissemination process from one that relies heavily on the unidirectional transfer of information from the academic setting to the stakeholder community, to a dynamic process that embraces partnership and multidirectional communication among researchers, educators, clinicians, policy makers, and the general public (Draper, Low, Withall, Vickland, & Ward, 2009). The DKT process also feeds ideas, perspectives, and questions to researchers that enable their work to be as up-to-date and responsive as possible. The results impart benefits along the entire continuum of wellness, from understanding of disease to patient care.

To this end, of three major themes that constitute the Network's overarching goals, one is entirely dedicated to the development of a curriculum map. Guided by principles of inquiry-based learning and reflective practice, a needs assessment was the first step. The results of the survey are the subject of this article and highlight the importance of bridging the dementia research-to-practice gap. We specifically examined the needs and priorities of dementia researchers toward the development of a tailored DKT curriculum that, together with other current efforts (e.g., Canadian Dementia Resource and Alzheimer Knowledge Exchange, 2010; Canadian Institutes of Health Research, 2010a; eHealthOntario.ca, 2010), will lead to the realization of these goals.

METHOD

We conducted a web-based survey of researchers in Canada who received dementia research funding from the Canadian Institutes of Health Research (CIHR) between 2004 and 2009, received research funds from the Alzheimer Society of Canada between 2004 and 2009, or are affiliated with the CDKTN. We contacted researchers by e-mail initially in late 2009 and followed up twice by e-mail at 2-week intervals to maximize participation.

The 35-question survey instrument was developed based on the Teaching Perspectives Inventory (Pratt, 2002). It was vetted among members of our team and advisors and refined based on their feedback. The final survey was offered in English and French and comprised 5-point Likert-type ranking, yes/no, and “choose all apply” questions. We encouraged participants to add open narrative comments to augment their answers. Our goal was to map the landscape of the DKT needs and priorities of dementia researchers, not to test a hypothesis about them per se. Therefore, the results reported here are descriptive and illustrate trends about interest, beliefs, goals, and outcomes for DKT. Key findings for DKT are displayed in tables or illustrated in figures; other data are reported in the text. The study was conducted with approval from the Behavioral Research Ethics Board of our institution.

RESULTS

Response Cohort

We received 173 completed surveys from 1,050 investigators invited to participate—a response rate of 16% that is consistent with other survey studies we have conducted of this nature (e.g., Illes, Tairyan, Federico, Tabet, & Glover, 2010). The majority of respondents are situated within a medical center or hospital affiliated with a university and self-identify as academic faculty, clinicians, or professionals (hereafter “faculty”) with applied or clinical research portfolios. Trainees (postdoctoral fellows, residents, graduate students, medical students) make up 18% of the sample (Table 1). Of the faculty group, 43% are the head of a department, unit, or equivalent organization.

Perspectives on DKT

DKT interest and duty. Eighty-seven percent of participants report interest (62/173; 36%) or high interest (88/173; 51%) in translating dementia-related knowledge. Ninety percent of respondents either agree (71/173; 41%) or strongly agree (85/173; 49%) with the statement that it is their “duty

TABLE 1 Demographics of the Study Population

Survey language	(<i>N</i> = 173)
English	160 (92%)
French	13 (8%)
Research position	
Academic faculty	124 (72%)
Trainee	32 (18%)
Other	16 (9%)
Undeclared	1 (1%)
Research type	
Applied/translational/clinical	214 (N/A) ^a
Basic science	60 (35%)
Other	17 (10%)
Highest degree attained	
PhD and/or MD	141 (82%)
MA/MSc (or equivalent)	19 (11%)
BA/BSc (or equivalent)	10 (6%)
Other	1 (1%)
Undeclared	2 (1%)
Research group head	
Yes	75 (43%)
No	92 (53%)
Undeclared	6 (3%)

^aValue exceeds total *N* as multiple response options were permitted.

to translate their work in order to improve practice,” and 34% (59/173) agree and 52% (90/173) strongly agree that DKT will “improve patient treatment and care quality.” The data further suggest that faculty and trainees share the belief that the “value of knowledge increases with [the] capacity to link it to practical contexts,” and that additional benefits accrue from “built-in feedback mechanisms” inherent in the KT process.

Faculty and trainees report that the primary practical challenge for DKT is patient-centered. For faculty, the challenges of interacting with patients with impaired communication (84/140; 60%) are key. Trainees report that a lack of definitive biomarkers for the disease and dynamic changes in the cognitive capacity of patients (17/32; 53%) present the greatest practical challenges. More faculty than trainees weigh issues related to care and resources—that is, access to long-term care and burden of decision-making on a person’s circle of care—as practical challenges for DKT (Table 2).

Current DKT strategies. Faculty report that they formulate their DKT strategies primarily based on the needs of their target audience (120/140; 86%); trainees base their strategies primarily on the type of results to be translated (26/32; 81%). To engage audiences in DKT, investigators report using prints of scholarly articles (168/173; 97%) primarily. Popular media (144/173; 83%), policy papers (137/173; 79%), Web-based resources

TABLE 2 Practical Challenges for Dementia Knowledge Translation

		Faculty (<i>n</i> = 140)	Trainees (<i>n</i> = 32)
Patient-centered issues	Communication challenges	84 (60%)	14 (44%)
	Dynamic changes in cognitive capacity of patients	67 (48%)	17 (53%)
	Changes in executive function and loss of autonomy	60 (43%)	9 (28%)
	Lack of definitive predictive biomarkers of the disease	55 (39%)	17 (53%)
	Lack of cure	55 (39%)	11 (34%)
Care and resources	Access to resources for long-term care	71 (51%)	10 (31%)
	Burden of decision making on circle of care (family and other carers)	67 (48%)	8 (25%)
Genetics and other	Costs of long-term care	43 (31%)	8 (25%)
	Other	29 (21%)	3 (9%)
	Implications of genetic susceptibility for families	27 (19%)	2 (6%)
	Implications of genetic susceptibility for ethnic groups	14 (10%)	3 (9%)

(129/173; 75%), unpublished reports (125/173; 72%), and case studies (109/173; 63%) are used more sporadically, albeit not infrequently. Fourteen percent of faculty (20/140) and 22% of trainees (7/32) report that they work with a local KT mentor.

Faculty report more extensive current involvement in DKT than trainees. They identify reforming dementia treatment and care (118/140; 84%), informing colleagues (109/140; 78%), improving interprofessional communication (104/140; 74%), and conveying actionable messages to policy makers (99/140; 71%) and health care administrators (98/140; 70%) as KT components of their professional practice (Table 3). Faculty also express greater interest than trainees in the different dimensions of translating knowledge for evidence-based practice, including demonstrating how research findings can be applied in practice (125/140; 89%), creating channels of communication for sharing relevant information (102/140; 73%), participating in dialogue among interprofessional groups (95/140; 68%), and discovering practice-related questions from peers (83/140; 59%; Table 4).

DKT Training Needs and Priorities

DKT training goals. Overall, respondents report that the key goals for DKT training are improving the ability to convey new knowledge to the public (faculty and staff: 82%; trainees: 81%), sharing information among different professional groups (faculty and staff: 78%; trainees: 75%), and formulating actionable messages to policy makers (faculty and staff: 69%;

TABLE 3 Role of Dementia Knowledge Translation in Professional Practice

		Faculty (<i>N</i> = 140)	Trainees (<i>N</i> = 32)
To improve communication among different professional groups	Seldom to never	8 (6%)	10 (31%)
	Sometimes	28 (20%)	6 (19%)
	Often to always	104 (74%)	16 (50%)
To continuously inform colleagues with new knowledge	Seldom to never	6 (4%)	4 (13%)
	Sometimes	25 (18%)	7 (22%)
	Often to always	109 (78%)	21 (66%)
To bring about changes in the treatment and care of dementia	Seldom to never	7 (5%)	9 (28%)
	Sometimes	15 (11%)	6 (19%)
	Often to always	118 (84%)	17 (53%)
To convey actionable messages to healthcare administrators	Seldom to never	14 (10%)	13 (42%)
	Sometimes	28 (20%)	7 (22%)
	Often to always	98 (70%)	12 (36%)
To communicate actionable messages to policy makers	Seldom to never	14 (10%)	13 (41%)
	Sometimes	27 (19%)	7 (22%)
	Often to always	99 (71%)	12 (37%)

TABLE 4 Primary Objectives for Translating Knowledge for Evidence-Based Practice

		Faculty (<i>N</i> = 140)	Trainees (<i>N</i> = 32)
Demonstrating how research findings can be applied in practice	Seldom to never	1 (1%)	3 (9%)
	Sometimes	15 (11%)	5 (16%)
	Often to always	125 (89%)	24 (75%)
Discovering practice-related questions from peers	Seldom to never	18 (13%)	9 (28%)
	Sometimes	39 (28%)	13 (41%)
	Often to always	83 (59%)	10 (31%)
Creating channels of communication for sharing relevant information	Seldom to never	8 (6%)	7 (22%)
	Sometimes	31 (22%)	4 (13%)
	Often to always	102 (73%)	21 (66%)
Participating in dialogue among interprofessional groups	Seldom to never	10 (7%)	7 (22%)
	Sometimes	35 (25%)	8 (25%)
	Often to always	95 (68%)	17 (53%)

trainees: 63%; Figure 1). As one faculty respondent wrote: there is a “lack of communication between [the] research community, healthcare workers, and general public.” Another faculty respondent highlighted the need for an “improved ability to work collaboratively with all stakeholders,” and a third commented that “knowledge translation has many levels, and training should be provided for each of these levels (the lay public, policy makers, GPs, students, colleagues . . .).”

Training opportunities to augment KT in grant applications are a high priority for trainees (30/32; 93% report moderate or high interest), as is learning community-based research—signified by the proportion of trainees who

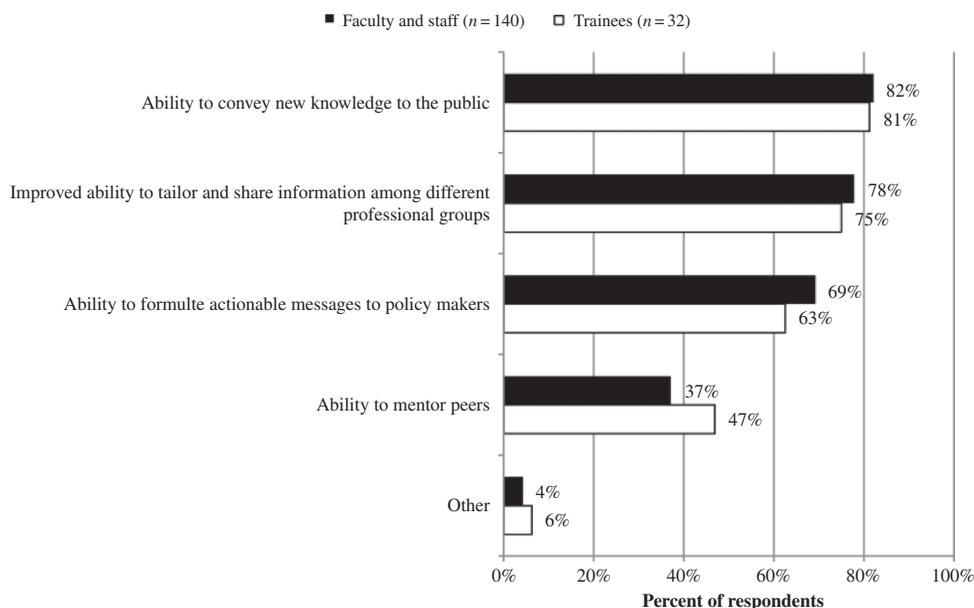


FIGURE 1 Goals for dementia knowledge translation.

report moderate (9/32; 27%) or high (18/32; 57%) interest. Among the faculty, 73% (102/140) report that training opportunities to learn about KT for grant applications is of moderate (41/140; 29%) or high (62/140; 44%) interest, and 63% (88/140) report either moderate (43/140; 31%) or high (45/140; 32%) interest in training for community-based research. Eighty percent of trainees (26/32), compared to 64% of faculty (90/140), report an interest in training opportunities for developing outreach programs. Trainees also suggest that mentoring peers (15/32; 47%), reflecting on professional practice (17/32; 53%), and functioning more effectively in the workplace (23/32; 72%) are primary training outcomes. Faculty wish to implement changes (97/140; 69%) and function more effectively (88/140; 63%) in the workplace.

DKT training and dissemination structure. Respondents overall favor workshops and seminars supplemented by self-paced programs offered over the Internet for DKT training (Figure 2). Faculty and staff prefer offsite training for workshops and seminars. More trainees than faculty report a preference for intensive training programs with certification. Online resources, in addition to printed handbooks on best practices, the services of local mentors, communities of practice, and case studies are each reported to be valuable supplemental training resources by more than 40% of respondents. Across the responding cohort, e-mail (126/173; 73%) and teleconferencing (80/173; 46%) and videoconferencing (74/173; 43%) are the preferred methods for disseminating information.

Incentives and barriers to engage in DKT. Principal motivators for DKT are increased funding support (faculty and staff: 74%; trainees: 63%),

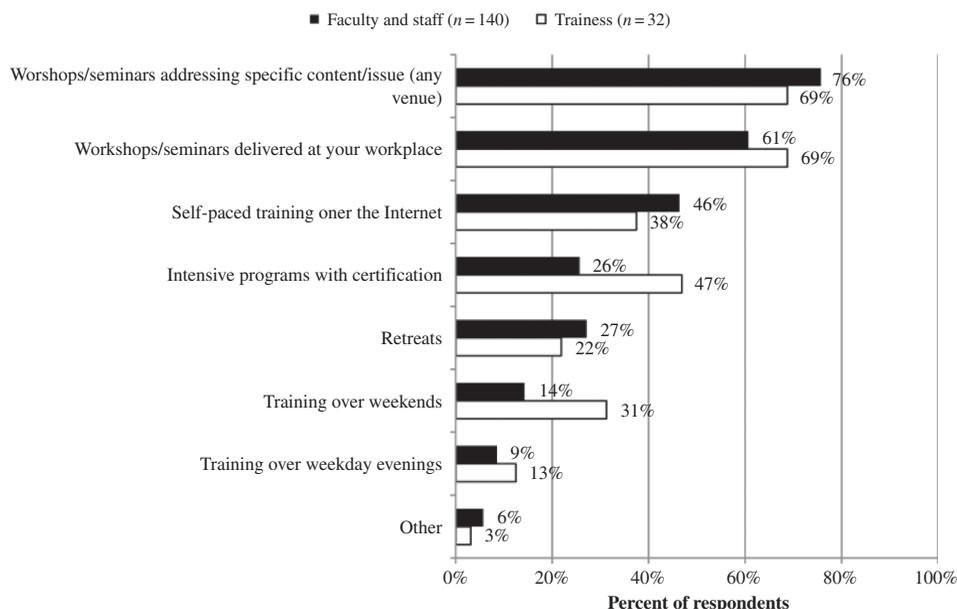


FIGURE 2 Preferred dementia knowledge translation training modes.

networking with colleagues at national and international levels (faculty and staff: 72%; trainees: 66%), and peer support and collaboration (faculty and staff: 70%; trainees: 75% Figure 3a).

Across respondent groups, principal barriers to KT are insufficient time (faculty and staff: 73%; trainees: 63%) and inadequate funding support (faculty and staff: 75%; trainees: 50%; Figure 3b). A lack of experience and lack of departmental support are more frequently reported as barriers by trainees than faculty.

DISCUSSION

Researchers from across Canada report strong interest in DKT and a sense of duty to translate knowledge about dementia. Respondents generally seek KT training in a format that is structured and interactive, that confers practical benefits and, as described by others, that promotes collaboration and interdisciplinarity (Qin, Lancaster, & Allen, 1997). As others have noted (McCrindle, 2006) generational differences influence priorities and preferences for training. Overall, informal and flexible learning materials (e.g., Web-based resources) are welcome supplemental resources to in-person workshops and seminars for DKT. That researchers across professional levels value the diversity of stakeholders in DKT, including policy makers and the general public, suggests that they view KT as a dynamic tool with broad

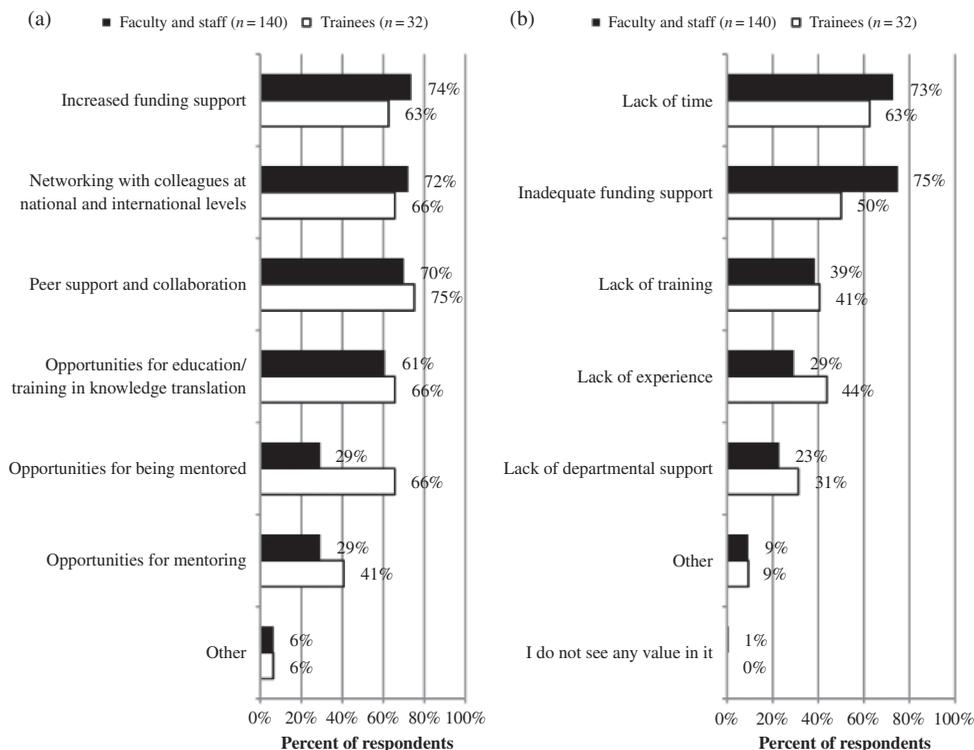


FIGURE 3 (a) Incentives for engaging in dementia knowledge translation. (b) Barriers to engaging in dementia knowledge translation.

applicability in a variety of contexts. Ultimately, well-developed DKT may serve to reverse the trend that researchers often feel “frustrated that their work isn’t used more widely by policy makers” (Dash, Gowman, & Traynor, 2003, p. 1339). Our data suggest that dementia researchers are receptive and ready to embrace resources and tools that can assist them to translate their research findings. Publications from the cancer (Grunfeld et al., 2008), chronic pain (Craig, 2008), and stroke research (Menon, Bitensky, & Straus, 2010) communities, among others, suggest that demand for KT programming is expanding across the health sciences.

The current study was a novel undertaking to characterize the DKT landscape that was largely undefined. The results are limited by the relatively small representation of the large number of investigators and health care providers in the area, and the disproportionate number of responses from faculty-level investigators. Respondents all hold funding for research and, by virtue of their participation, are likely to have had prior interest in KT.

Despite these limitations, we have learned that the development and testing of tailored curricula in DKT are the important next steps in creating a dementia research community skilled in the science of KT. KT planning tools (Landry, 2010), KT casebooks (Canadian Institutes of Health

Research, 2008a), and online KT learning modules (Canadian Institutes of Health Research, 2010b) are all models upon which we can build. Other programs for translation of dementia-related knowledge to health professionals, policy makers, and members of the general public highlight different approaches to engage a variety of stakeholder populations in DKT. For example, Cafés Scientifiques funded by CIHR Institute of Aging (IA) and other institutes highlight innovative research to a lay audience focused on the health of the aging population (Canadian Institutes of Health Research, 2010a). In the province of British Columbia, Northern Health (2010) has a Dementia E-learning program geared to linking persons with dementia, their caregivers, health care delivery professionals, and members of the public with up-to-date information and support resources. The Alzheimer Society of Canada (2010b) recently unveiled a document targeted to health policy makers, assessing the social and economic impacts of dementia in Canada. The comprehensive policy brief provides a series of concrete recommendations for how to address the issue of increasing dementia care costs while also weighing the social ramifications of these options. Resources such as these underscore how dementia-related knowledge developed at the bench can be translated to a variety of audiences using a range of different media. Recently, *The Globe and Mail*—Canada's largest circulation national newspaper—featured a week-long series of articles about dementia and related disorders (Picard, 2010), an undertaking for which impact on DKT remains to be seen.

Closing the loop for enhanced and relevant research questions through further DKT initiatives will improve the alignment between research and care (Kerner, 2006). Innovative curricula and training initiatives that are tailored to the specific needs and priorities of dementia researchers and assessment and continuous refinements that are adapted to the evolving needs of the research community will be essential to attract researchers to DKT and ensure enduring effectiveness of DKT programming.

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