IMPLEMENTATION AND SYSTEMATIC EVALUATION OF A KNOWLEDGE TRANSLATION INITIATIVE FOR IMPROVED PAIN MANAGEMENT AND ASSESSMENT IN DEMENTIA

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Abstract

Pain is highly prevalent in older adults with dementia. Despite this, pain is routinely underassessed and undertreated in this population. Although a wealth of research has been produced in this area, transforming evidence into impactful action in practice often presents numerous barriers. As such, a recent area of emphasis in science is evidence implementation. Knowledge translation (KT) refers to the iterative process by which research is implemented into health systems (e.g., hospitals) to advance knowledge, inform future research questions, and improve health outcomes. Recent social media (SM) KT initiatives have demonstrated success in expanding the access to health information and mobilizing solutions; however, there is a lack of research examining KT initiatives for older adults. The primary goal of this study is to implement and evaluate a large-scale KT initiative (i.e., the #SeePainMoreClearly initiative) aimed at increasing awareness, uptake, and access to evidence-based information about pain in dementia. The study included the creation of an online repository and engaging evidence-based content and dissemination through SM. The effectiveness of the project was evaluated through various web analytics, SM metrics, and questionnaires. Quantitative analysis of SM metrics indicated a great scope and reach of the initiative. Evaluation questionnaire ratings demonstrated evidence of improved understanding about the problem of pain in dementia and the current solutions among health professionals, caregivers, and members of the public. Textual data from SM discussions showed that the #SeePainMoreClearly initiative stimulated online discussion about pain in dementia. Findings from this investigation have implications for closing the knowledge to practice gap in dementia care through faster mobilization of scientific findings. The methodologies used in the study could serve as a framework for the development of social media KT initiatives in other health disciplines.
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1. INTRODUCTION

1.1 Overview

Canada’s population is undergoing a rapid demographic shift. It is projected that by 2033, Canadians over 65 years old will account for 25% of the population (Statistics Canada, 2019). This shift is seen across the world and has led to an increase in the volume of age-related research (Vasunilashorn, Steinman, Leivig, & Pynoos, 2012). Despite the large monetary amounts invested to support health research each year (Canadian Institutes of Health Research, 2019), there is a pattern of promising research evidence not leading to improvements in health outcomes (Macleod et al., 2014). For instance, pain-related conditions continue to account for 80% of physician visits in Canada and cost $6 billion each year (Choiniere et al., 2010). As a result, increasing emphasis is being placed on mobilizing available research findings. Implementation of pertinent scientific information is imperative for the older adult population, who experience increasing prevalence of pain with age (Helme & Gibson, 2001).

The International Association for the Study of Pain (IASP) (2012) characterizes pain as a subjective and “unpleasant experience associated with actual or potential tissue damage or described in terms of such damage.” Pain, as a symptom, is highly prevalent in older adults (Molton & Terrill, 2014; Tsang et al., 2008). This is concerning given that chronic pain is associated with numerous negative psychological and physical consequences such as sleep deprivation, increased risk for depression, social isolation, and impaired physical functioning and activity (Almedia et al., 2012; Chen, Hayman, Shmerling, Bean, & Leveille, 2011; Gleicher, Croxford, Hochman, & Hawker, 2011; Jensen, Moore, Bockow, Ehde, & Engel, 2011).

1.2 Pain in Dementia
The prevalence of pain is magnified in long-term care (LTC) facilities, where as many as 80% of residents suffer from pain (Helme & Gibson, 2001). Increasing cognitive impairments associated with severe dementia often compromise individuals’ ability to effectively communicate their pain experience (Herr, Bursch, Ersek, Miller, & Swafford, 2012; Kaasalainen, Akhatar-Danesh, Hadjistavropoulos, Zwakhalen, & Verreault, 2013). Responsive behaviours (e.g., aggression, agitation) are common among patients with dementia and have been identified as behavioural manifestations of pain (Cohen-Mansfield & Lipson, 2006; Testad, Aasland & Aarsland, 2007). Pain assessment tools that rely on self-report may not be appropriate for older adults with moderate to severe dementia because of their limited ability to communicate due to cognitive and linguistic impairments (Horgas, Elliot, & Marsiske, 2009; Pautex et al., 2006). Evidently, pain is a complex experience and presents many challenges to patients, caregivers, and health professionals; yet despite these challenges, clear guidance for evidence-based pain assessment and management in dementia exists (Fuchs-Lacelle & Hadjistavropoulos, 2004; Hadjistavropoulos et al., 2014; Hadjistavropoulos et al., 2009).

**Knowledge Gaps in Long-term Care Settings.** A large body of research has examined and validated the use of observational pain assessment tools to assess non-verbal pain cues in older adults with severe dementia (Abbey et al., 2004; Fuchs-Lacelle & Hadjistavropoulos, 2004; Snow et al., 2004; Warden, Hurley, & Volicer, 2003). The regular use of these tools has been shown to improve pain management practices (e.g., reducing polypharmacy, improving pain levels) and reduce nursing staff stress in long-term care (LTC) settings (Hadjistavropoulos, Kaasalainen, Williams, & Zacharias, 2014; Fuchs-Lacelle, Hadjistavropoulos & Lix, 2008). Moreover, systematically managing pain significantly reduces responsive behaviours and unnecessary prescription of psychotropic medications (Husebo, Ballard, Sandvik, Nilsen, &
Aarsland, 2011; Husebo, Ballard & Cohen-Mansfield, Seifert, & Aarsland, 2014). Cost-effective and feasible clinical and public policy guidelines for improved pain assessment and management have also been outlined (Hadjistavropoulos et al., 2009). A survey of LTC front-line staff and administrators in three Canadian provinces indicated strong acceptance of and willingness to adopt these guidelines in clinical practice (Hadjistavropoulos et al., 2011). However, there is a disconnect between prevailing practices and the literature.

Pain is consistently underassessed and undertreated in older adults with dementia (Lautenbacher, 2014). Reynolds, Hanson, DeVellis, Henderson and Steinhauser (2008) reported disparities in the level of pain reported by the nursing staff between residents with dementia and residents without cognitive impairments in LTC facilities. Reported pain instances were lower for individuals with declining cognitive abilities (Reynolds et al., 2008). Consequently, individuals with severe cognitive impairments received significantly lower pain-relieving medications compared to individuals without cognitive impairments (Reynolds et al., 2008) despite similar prevalence of pain-related conditions (Balfour & O’Rourke, 2003). In addition, responsive behaviours that are associated with pain are often misattributed to psychiatric disturbances leading to treatment using psychotropic instead of analgesic medications (Ahn & Horgas, 2013; Husebo et al., 2008; Husebo et al., 2011; Pieper et al., 2013; Tosato et al., 2012). Psychotropic medications have been shown to hasten death in this population (Banerjee, 2009; Maust et al., 2015). In sum, despite the availability of evidence-based methods for evaluating and managing pain in dementia, clinical practice lags behind the research. This exemplifies the knowledge to practice gap in health care. Implementation of available evidence-based approaches is paramount to improving the quality of life of older adults with severe dementia.

1.3 Knowledge Translation
The World Health Organization (2019) defines knowledge translation (KT) as “the synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and advancing people’s health.” This parallels the Canadian Institute of Health Research’s (CIHR) (2016) definition of KT as “a dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the healthcare system.” Evidently, research production and implementation are necessary components to advancing knowledge and improving health outcomes. Although an abundance of research is synthesized each year, transforming the evidence and semantics embedded in scientific articles into impactful and dynamic action in practice often encounters numerous barriers (Bigham et al., 2010; Lang et al., 2007; Mertzer & Metz, 2010; Wensing, Bosch, & Grol., 2010). Cabana et al. (1999) outlined access to information, volume of information, and contradictory information as possible barriers to the uptake of research findings. In addition, costs and human resource limitations have been identified as key impediments to implementation (Lang et al., 2007).

These factors hinder effective translation of research to practice and policy leading to many patients failing to receive effective treatments and high-quality health care information (Shuster, McGlynn, & Brook, 1998; Grol, 2001; McGlynn et al., 2003). It has been demonstrated that 30 to 40% of patients do not receive optimal evidence-based care and that there is great variability in the type of care that health professionals deliver despite clear scientific consensus (Albrecht, Archibald, Snelgrove-Clarke, & Scott, 2016; Campbell, Louie-Poon, Slater, & Scott, 2019; Freedman et al., 2011; Johnson et al., 2006; Hampers & Fries, 2002). Moreover, despite extensive efforts to implement the best evidence-based information, gaps in practice still persist.
For example, the Ottawa Ankle Rules is a bedside instrument created in the 90s to assist health professionals in determining patients who may forgo unnecessary radiography tests (Stille et al., 1992). Sensitivity analysis, clinical and diagnostic accuracy, impact analyses, and randomized control trials have provided substantial support for the feasibility and efficacy of the instrument in reducing radiography tests (Audeley et al., 1997; Bachmann, Kolb, Koller, Steurer, & ter Riet, 2003; Stiell et al., 1992; Stiell et al., 1995). A survey of 1,769 emergency physicians indicated that as many as 90% of Canadian and American respondent physicians were aware and familiar of the Ottawa Ankle Rules; however, only 17% of Canadian physicians reported to using the instrument frequently (Graham et al., 2001). In addition, a 2006 survey revealed that although many physicians reported being familiar with the rules, only 31% remembered the components of the instrument (Brehaut, Stiell, Visentin, & Graham, 2006).

**Knowledge Translation Methodologies.** Evidently, altering clinical practices is complex and challenging. In the same way that design and methodologies are integral to the successes and pitfalls of executing a research study, the modalities used in the KT process may contribute to the inefficiencies in implementation. Although there is a dearth of related literature focusing on KT initiatives for older adults (Ellen, Panisset, de Caravalho, Goodwin, & Beard, 2017), there is research outlining methods applied in other health care domains. A systematic review of KT approaches for pediatric pain revealed that in-service training and workshops are predominantly used as forms of knowledge transfer; although these methods increase knowledge and satisfaction among participants, they have failed to demonstrate sustainability (Gagnon, Hadjistavropoulos, Hampton, & Stinson, 2016). A single modality approach is incongruent to the complexity of the healthcare system. As a result, multifaceted KT interventions (e.g., educational meeting/component, computerized decision support, multidisciplinary teams) have been adapted
in health care settings (Bernstein et al., 2013; Real et al., 2017; Zurovac et al., 2011).

Interestingly, Campbell et al. (2019) found that the most effective approach used by health care professionals in pediatric health settings utilized online and/or computerized KT methods.

An understanding of the complexity of the health care system also includes being cognizant of all knowledge users that may benefit from the research. As outlined, KT approaches have mainly focused on health professionals as the primary targeted audience of KT efforts (Chiang, Chen, & Huang, 2006; Corwin, Kessler, Auerbach, Liang, & Kristinsson, 2012; Dunbar et al., 2006; Farahani, Alhani, & Mohammadi, 2014; Jayaram, Nagel, & Jasty, 2010; Stevens et al., 2014). The integrated knowledge translation (IKT) approach aims to address this; IKT refers to a symbiotic and collaborative knowledge exchange and partnership between those who produce the research (e.g., researchers) and those who may benefit from the research (e.g., patients, clinicians, policymakers, etc.) (Gagliardi, Berta, Kothari, Boyko, & Urquhart, 2015; Kothari & Wathen, 2013). An IKT approach can facilitate the generation and implementation of knowledge by allowing varied expertise and enhanced dialogue among all knowledge users to better inform research practice and design (Lohr & Steinwachs, 2002). Integrated KT approaches have been demonstrated to enhance policymaking, service delivery, and awareness of knowledge (Gagliardi et al., 2015).

In sum, the knowledge to practice gap is influenced by a myriad of factors. As the IKT model illustrates, there is a crucial need to diversify dissemination approaches and practices if researchers intend to engage all knowledge-users and generate sustainable impact. This includes ensuring that targeted viewpoints are well represented in the research and dissemination processes. This gives support for the need to further establish a methodology to facilitate comprehensive knowledge translation and explore online knowledge mobilization efforts.
1.4 Social Media for Scientific Dissemination

The advent of technological advancements, such as the Internet, has allowed for unprecedented communication and interactions among people from all over the world. In particular, social media (SM) platforms are fostering a sense of interconnectedness among individuals and communities that transcend geographical barriers (Colliander & Dahlen, 2011; Ngai, Tao, & Moon, 2015). Social media refers to web-based networks or platforms where individuals can share and discuss user-generated content (Kietzmann, Hermkens, McCarthy, & Silvestre, 2011). Social media networks (e.g., Facebook, Twitter, Instagram) are ubiquitous, easy to use and vary in functionality and utility (Kietzmann et al., 2011). Over 94% of Canadian adults use at least one SM platform, with Facebook, YouTube, LinkedIn, Twitter and Pinterest among the five most widely used platforms (Gruzd, Jacobson, Mai, & Dubois, 2017). In addition, Chou, Hunt, Beckjord, Moser and Hesse (2009) found that SM use is consistent among groups regardless of education, ethnicity and health care access. The proliferation of SM networks across many groups brings unique dissemination opportunities for health researchers.

Social Media Approaches. In recent years, there has been an exponential and varied use of the Internet as a means of disseminating health information (Fahy, Hardikar, Fox & Mackay, 2014; Scanfeld, Scanfeld & Larson, 2010). For example, an IKT initiative in the area of emergency medicine utilized an online repository of evidence-based information and social networks to maximize reach and engagement (Featherstone et al., 2016). Featherstone et al. (2016) used web and SM analytics to track website visitors and SM engagement. The online repository was viewed by over 1,200 individuals per month and survey responses indicated that the resources were valuable and informative (Featherstone et al., 2016). Moreover, Friedman et
al. (2016) outlined that combining SM resources with in-person KT further increases public awareness and participant engagement.

More recently, Chambers’ (2018) “#ItsNotHurt” SM initiative in the area of pediatric pain generated worldwide impact and demonstrated changes in parent behaviors beneficial to vaccination pain management. The initiative had great success in producing and disseminating various digital evidence-based content using videos, blog posts, and images tailored to the needs of parents and health professionals (Chambers, 2018). For example, a brief YouTube video on pediatric vaccination pain management strategies has been viewed over 230,000 times in 180 countries (Chambers, 2018). Another innovative SM approach that has been used in health research is social listening (Heldman, Schindelar & Weaver, 2013; Powell et al., 2016). Social listening is a strategy of tracking trends and conversations about a topic through SM platforms (Pomputuis, 2019). The approach has been employed by organizations to assess user needs and gain unfiltered feedback (Pomputuis, 2019). Cole-Lewis et al. (2015) analyzed historical Twitter data for trends in people’s knowledge and behaviours about electronic cigarette use to help inform public and health policy. The authors expressed that social listening allows researchers to access a breadth of data from individuals (e.g., minorities) who are often underrepresented in research (Cole-Lewis et al., 2015).

1.5 Purpose

Caregivers and patients are increasingly turning to SM to access and share health information (Gage-Bouchard, LaValley, Mollica & Beaupin, 2017; Hamm et al., 2013). Moreover, individuals over 65 years old indicate searching online sources for health information (Fox, 2011). Social media has the potential of overcoming delays associated with more traditional KT modalities by expediting the spread of information and allowing researchers to directly interact
with stakeholders (e.g., caregivers/family members, health professionals) around the world. Thus, implementing a social media led initiative in the framework of an IKT approach may lead to broader and faster societal impact; however, there is very little precedent in systematically developing and evaluating a large-scale KT initiative in the area of pain for older adults with dementia.

The primary purpose of this study is to implement and evaluate a KT initiative using social media to disseminate scientific information to improve the quality of life of older adults with dementia through better pain assessment and management. More specifically, the aim of the study is to increase awareness, accessibility, and uptake of evidence-based solutions and practices about pain in dementia to patients, caregivers, health professionals, policy makers, and the public at large. The research questions examined are: 1) What is the reach and scope of a large-scale social media KT campaign? 2) Does a social media KT initiative facilitate the uptake of evidence-based information by increasing online discussions about pain in dementia? and 3) What is the impact of the campaign on patient/caregiver/health professional knowledge and behaviour? These questions provided the framework for the development design and evaluation methodology of the study.

2. METHOD

2.1 Development

In line with an IKT approach, front-line health professionals (e.g., nurses), caregiver partners, and organizations (e.g., Canadian Association on Gerontology, AGE-WELL Network of Centre of Excellence, Chronic Pain Network, and Alzheimer Society of Saskatchewan) were involved in developing, implementing, and disseminating the evidence-based content and social media strategy. Communication was sustained through in-person/telephone meetings and email. The
development plan will be consisted of a) creating an online repository; b) creating engaging evidence-based content; and c) social media dissemination.

**Online Repository.** A web-based repository (www.seepainmoreclearly.org/resources) of evidence-based information about pain in dementia was created specifically for the project. Information was presented in various mediums. As an example, the Pain Assessment Checklist for Seniors with Limited Abilities to Communicate (PACSLAC-II), a well-validated pain assessment observational tool, was made available for researchers and health professionals upon request (Chan, Hadjistavropoulos, Williams, & Lints-Martindale, 2014). In addition, a web-based assessment training program for LTC staff using the PACSLAC-II was provided. Evidence-based information were also presented through scientific articles and webinars by researchers from a variety of fields (e.g., psychology, nursing, computer science, engineering). Other external online resources (i.e., provided by geriatric.org and alzheimer.ca) were also included in the website.

**Evidence-based Content.** In addition to the web-based repository, and with the goal of diversifying the way that information is delivered, evidence-based information was transformed and curated into multimedia content (e.g., video, photos, and articles). Figure 1 outlines examples of the evidence-based content produced during the initiative. Research information was summarized into easily understood and distributable content. This was used to capitalize on knowledge-user engagement and tailor information for all knowledge users. As an example, a short two-minute video about pain in dementia was developed and uploaded to YouTube titled “Pain in Dementia #SeePainMoreClearly” (https://youtu.be/9ONjQ7_ZvZA). The video depicts the following scenes: an older adult with severe dementia who is showing responsive behaviours (e.g., agitation), the nursing staff then having difficulties understanding that he is in pain, the
next scene is narrated by the same older adult at an earlier stage of his life in which he offers guidance and evidence-based solutions for his future caregivers. The script for the video was created and modified with input from health professionals, caregiver partners, researchers, and organizations. Paid promotions (i.e., a total of $540.00) through Google/YouTube advertisement were utilized from January 4th to February 15th for the short YouTube video.

**Social Media Initiative.** The University of Regina Centre on Aging and Health and Health Psychology Laboratory Twitter accounts were primarily used to disseminate information and initiate a large-scale social media campaign. The #SeePainMoreClearly hashtag was created to capitalize on user engagement. This hashtag was vetted, and input was solicited from partners in order to ensure that the intended message of the campaign is captured. Moreover, the campaign launched on October 1st, 2019 the International Day of Older Persons. Paid promotion (i.e., approximately $390.00) through Twitter advertisement were utilized from November 20th to November 27th.

### 2.2 Evaluation and Measures

**Social Media Monitoring and Listening.** A social media monitoring/listening software Keyhole (2019) was used to monitor the number of Twitter impressions (i.e., the number of times that users have seen the online content), reach (i.e., the number of unique users who has seen the online content), engagement (i.e., re-tweets and likes), and posts using the hashtag created for the campaign. Public demographic information about the content viewers (e.g., gender, country) was collected. Social listening was conducted by collecting tweets from the control period (October 1st, 2018 to February 28, 2019) and the evaluation period (October 1st, 2019 to February 28, 2020). The data was subjected to content analysis.
**Video Evaluation Questionnaire.** An evaluation questionnaire (see Appendix A) was created for the purposes of the study. The survey includes general and specific questions for the public, health professionals, caregivers/family members of people with dementia, people with dementia and policy makers. As such, depending on the group that content viewers identify with, the number of questions varied. The questionnaire includes 8 to 15 items rated on a 7-point Likert scale according to viewers’ impressions and opinions about the short informational video and their likelihood to use the information in the video (i.e., some items range from 0 (i.e., not very likely) to 6 (i.e., very likely). In addition, the questionnaire includes open-ended questions. The survey also contains demographic information questions about their age, gender, country, and occupation. The questionnaire was administered through Qualtrics and was tied to the end of the short informational video, website, and social media messaging.

3. DATA ANALYSIS

3.1. Quantitative Analysis

**Social Media Analysis.** The reach, scope, and engagement of the project were monitored using various social media metrics (e.g., web analytics, hashtag analytics, Twitter analytics, YouTube views). These metrics have been outlined in previous research to quantify the broad impact of social media initiatives (Chambers, 2018; Featherstone et al., 2016). Social media networks (e.g., Twitter and YouTube) and the Keyhole (2019) social monitoring software were used to extract the data. In addition, the number of content viewers and engagement in the online repository were tracked using Google Analytics (Google, 2020). The number of media stories focusing on the campaign were also tracked as evidence of impact.
**Descriptive Statistics.** Descriptive statistics were used to calculate means and standard deviations for the Likert scale items in the evaluation questionnaire. Demographic questions were also be outlined using descriptive statistics.

**Analyses of Variance (ANOVA).** To examine differences in ratings among respondent groups (i.e., health professionals, public, caregivers/family members, policy makers) on questions (see Appendix A) regarding their 1) impression on the use of social media for scientific dissemination; 2) information-seeking behaviour; 3) impression of the video; and 4) level of new information provided, four one-way ANOVAs were conducted.

### 3.2 Analysis of Social Media Content

**Rate of Online Discussions.** The rate of online discussions will be determined from the data collected by Keyhole (2019). A search for tweets containing the hashtags “#pain #dementia” AND/OR key words “pain dementia” was conducted and identified tweets were examined for the control and evaluation periods. The rate of online discussions was calculated by obtaining the total number of tweets divided by the number of weeks per period (N/20). The rate of the two periods were compared.

**Content Analysis.** Social media messages (e.g., Tweets) from users who used the hashtag (i.e., #SeePainMoreClearly) or responded to the messaging and content posted on Twitter were subjected to a content analysis (White & Marsh, 2006). The data analyzed were first established according to the hypotheses of the study (White & Marsh, 2006). As such, preliminary inclusion and exclusion criteria for the data included in the analysis were determined and certain posts were omitted from the analysis: 1) re-tweet posts (i.e., non-original tweets); 2) tweets made from the research group and the researchers’ personal Twitter accounts; and 3) tweets containing only of the hashtag. A coding scheme was developed according the nature of
the tweets, motivation behind the tweets, and general type of tweets produced during the initiative. The responses were collected and coded to examine for common themes.

4. RESULTS

4.1 Media stories

The number of media stories were tracked throughout the campaign as evidence of impact. Among the ten media stories that covered the initiative, 4 were recorded interviews (e.g., CBC Saskatchewan, CTV Regina Live, CBC Radio, and 770 CHQR Radio Calgary) and 6 were written interviews/stories (e.g., Leader Post, University of Regina Discourse Magazine, Relief Magazine, Canadian Institutes of Health Research, and Dementia Connections).

4.2 Social Media Analytics

Hashtag Analytics. The social media metrics for a 5-month period from October 1, 2019 to February 29, 2020 were tracked. The hashtag #SeePainMoreClearly garnered 5,748,917 Twitter impressions, representing 2,376,853 users (i.e., also categorized as the “reach” of the hashtag) have seen or interacted with the hashtag (e.g., tweeted using the hashtag, retweeted). Moreover, a total of 2,905 posts (75% Re-tweets; 16.15% original tweets; 8.43% reply tweets) were made using the hashtag during this period from 578 individuals (89.6% females, 10.6% males). The hashtag was used in 31 countries, with 20% of the interactions occurring in countries outside of Canada. Sixty-eight percent of the users used mobile phones to interact with the hashtag.

Online Repository. The online repository of resources and information was tracked for the 5-month period. A total of 1,218 individuals (54% male, 46% female) viewed the website from 55 countries. Moreover, the website pages were viewed a total of 5,751 times.
**Informational Video Analytics.** Over a 5-month period, the video was viewed 50,880 times, and garnered over 150,578 impressions on YouTube. The video was viewed by 48,861 users (64% male, 36% female) and 34% were over 55 years old.

**4.3 Short Informational Video**

**Questionnaire Responses.** Eighty-three participants responded to our video evaluation questionnaire and 68 (81.9%) of those participants successfully completed the questionnaire by answering all the questions. Participant characteristics are outlined in Table 1. The impact of the informational video on self-reported knowledge about pain in dementia is outlined in Table 2. Among the respondents, 27.9% (N = 19) were caregivers or family members of a person with dementia, 33.8% were health professionals (N = 23), and 36.8% (N =25) were members of the public. Fifty-two percent (N = 35) of the respondents indicated that they followed the link to the website after viewing the video and 74.6% (N = 50) indicated strong willingness to send the video to others. Among health professionals, 69.6% (N = 16) indicated that they were now more likely to recommend regular and systematic evaluation of non-verbal signs of pain after viewing the video. Moreover, more than half (N =14) of members of the public indicated an improved understanding for the way pain may affect people with dementia after viewing the video. A majority of caregivers or family members of people with dementia (68.4%) indicated that greater likelihood of speaking to a health professional about the possibility that some responsive behaviours may be due to pain after watching the video.

**Comparisons by Respondent Background.** A summary of respondent responses based on impression on the use of social media for scientific dissemination, information-seeking behaviour, impression of the video, and level of new information provided is outlined in Table 3. To explore the possibility of response differences as a function of respondent background (e.g.,
health professionals, public, caregivers), four one-way ANOVAs were conducted. The results indicated no significant difference among ratings based on: 1) impression on the use of social media for scientific dissemination, F(2, 64) = 1.729, p = 0.186; 2) information-seeking behaviour, F(2, 64) = 1.087, p = 0.344; 3) overall impression of the video, F(2, 66) = 2.591, p = 0.083; and 4) level of new information provided, F(2, 64) = 0.288, p = 0.751.

### 4.4 Social Media Content

Using a social listening software (Keyhole, 2019), tweets about pain in dementia including keywords “pain in dementia” or “#pain #dementia” were scoped. For the control period (i.e., October 1, 2018 to February 28, 2019) a total of 4,631 tweets were made. For the evaluation period (i.e., October 1, 2019 to February 28, 2020), a total of 9,531 tweets were made about pain in dementia. This resulted in online discussion rates of 231.55 tweets/week during the control period and 476.55 tweets/week during the evaluation period about pain in dementia.

### 4.5 Content Analysis

Online discussions (N = 280) were subjected to a content analysis (White & Marsh, 2006). Three content themes emerged from the data: 1) sharing resources disseminated by the initiative; 2) comments about the resources or initiative; and 3) personal experiences.

**Disseminating Resources.** A total of 122 (43.6%) tweets shared the resources disseminated by the initiative (e.g., tweets that included online links to the video, resources, or webpage). Among these tweets, 69.5% (N = 85) indicated the need to share resources to mobilize solutions and increase awareness. The following tweets illustrate content pertaining to sharing resources to mobilize solutions and increase awareness:

- “More than half a million Canadians are living with #dementia, and about 25,000 new cases are diagnosed each year. People with severe #dementia often suffer from #pain
in isolation. Watch [and] share this video. Help us #SeePainMoreClearly.”

- “@URHealthPsycLab and team are launching a knowledge mobilization campaign on pain in dementia. Watch this 2-minute video to help spread the word and help find solutions. https://t.co/FzyPyEJDLo #IDOP2019 #UNIDOP @UofRAgingCentre #SeePainMoreClearly.”

- “It is even more paramount that patients with the inability to communicate their pain receive increased pain assessments. Check out this video from @URHealthPsycLab: https://t.co/dZ0D5sRqrM #NPAW2019 #LivingWithPain #Stroke #CPSP #SeePainMoreClearly https://t.co/wRKVLyyNOy.”

- “People with severe #dementia often suffer from unrecognized #pain. Watch @AGEWELL_NCE funded 2-minute video to help spread word & find solutions https://t.co/CSclw043qg #SeePainMoreClearly #IDOP2019 #UNIDOP #caregivers @URHealthPsycLab @UofRAgingCentre.”

Thirty-seven (30.3%) tweets shared the resources to show support for the initiative. The following tweets illustrate this:

- “We support @URHealthPsycLab and their knowledge mobilization campaign on pain in dementia. Watch this 2-minute video…https://t.co/2moLbQprwo #SeePainMoreClearly #IDOP2019 #UNIDOP @URHealthPsycLab @UofRAgingCentre.”

- “A colleague of mine @URHealthPsycLab is doing extremely important research toward improving pain assessment/management in people with #dementia. Please check out https://t.co/69JISsW4B9, RT, and/or consider completing the short survey. #seepainmoreclearly TY! #alzheimersdisease.”
It our pleasure to support the @URHealthPsycLab social media campaign to disseminate information about pain in dementia. Watch their video…https://t.co/pERzeVF9yb #SeePainMoreClearly #IDOP2019 #UNIDOP https://t.co/2Yy42kHyRX.”

“[We] support @URHealthPsycLab and their knowledge mobilization campaign on pain in dementia. Watch this 2-minute video to help spread the word and find solutions. https://t.co/3P9EMUkPQY #SeePainMoreClearly #IDOP2019 #UNIDOP @UofRAgingCentre.”

Comments About the Resources or Initiative. A total of 119 (42.5%) tweets provided feedback on the nature of the resources disseminated throughout the campaign or about the initiative as a whole. Among those tweets, 63.0% (N =75) commented on the significance of the campaign. The following tweets illustrate this:

- “#seepainmoreclearly campaign aims to raise awareness of the problem of pain under-diagnosis and under-treatment in #dementia.”
- “I love the work that's being done in this lab. The #SeePainMoreClearly initiative is bringing awareness to the experience of #pain in those living with #dementia…”
- “#SeePainMoreClearly sounds like a great campaign! There's lots about pain in ppl [with] #dementia and learning disabilities…”
- #NursingKnows the importance of #SeePainMoreClearly campaign, help spread the word, @LouiseCastiillo w/@UofRegina are doing important work for seniors…”

Moreover, 37.0% (N =44) of the tweets indicated that the short informational video or resources provided on the website were beneficial. The following tweets illustrate this:

- “The video highlights an essential part of caring for someone living with dementia.
Knowledge Translation for Pain in Dementia

It's important to be able to recognize symptoms of pain. #Dementia

#DementiaAwareness #SeePainMoreClearly.”

- “This is brilliant. Well done. Yes, people suffering from dementia are people too. They experience pain and may not understand it. Dementia sufferers live in the moment. A moment of pain can be an eternity, intolerable.”

- “A must watch. Look at his face, I can see the #pain. #Alzheimer patients are no different than all patients, they deserve proper pain assessment. #SeePainMoreClearly”

- “The message in this video is clear: consider pain as a problem in the person with dementia, assess, and respond, appropriately.”

**Personal Experiences.** A total of 39 (13.9%) tweets shared personal experiences using the hashtag or in response to the content produced during the initiative. The following tweets illustrate this:

- “As a caregiver, [one] of my main concerns was making sure my mother's pain was safely under control. She could no longer manage her meds without help. I did the best I could. Her pain was constant & varied. I had to adapt her pain signals with dementia.”

- “Having had an incredible grandmother who suffered from dementia for several years, I can personally attest to the impact of under assessment/management of pain in #dementia…”

- “I imagine many will have an "unrecognized pain in dementia" story. My most dramatic example is someone admitted to our dementia unit with "severe, treatment-resistant agitation." Staff note blood in stool. The patient has a large, nearly obstructive, rectal mass.”
“OMG thank you! My mother and I have tried to get her help but the doctors in our area...are too scared...to give her pain pills. One doctor said she was faking her pain. It's a nightmare watching a loved one suffer so horribly.”

5. DISCUSSION

The present study seeks to answer questions about the reach and scope of a large-scale social media KT campaign about pain in dementia, the effectiveness of the initiative to facilitate the uptake of evidence-based information, and the impact of the campaign on caregiver, health professional, and public knowledge and behaviour. First, the results of this investigation demonstrated the large scope of a SM initiative, comparable to the size outlined in previous research (Chambers, 2018) for a five-month evaluation period. Social media analytics indicated that the hashtag was used in 31 countries and the website was visited by individuals in 55 countries. As such, the information and message shared in this initiative diffused and reached knowledge-users across Canada and beyond. Moreover, the effectiveness of social media as a KT and dissemination tool was demonstrated in the number of engagements, impressions, views, posts, and media stories about the initiative.

Second, findings suggest that SM was able to facilitate the spread and uptake of evidence-based information. Results from comparison of online discussions about pain in dementia indicate that the rate of online discussions on Twitter was greater during the initiative period in comparison to rate of discussions in the previous year. This contributes to continuing education regarding pain assessment and management for this population. Furthermore, responses on the video evaluation questionnaire demonstrated information-seeking behaviour as a result of watching the video and a strong willingness to share the video to others. A majority of the respondents indicated strong agreement for effectiveness of social media in scientific
dissemination. Moreover, the results from content analysis of tweets made using the hashtag or in response to the content disseminated throughout the initiative suggest that a majority of individuals tweeted by sharing a link to video or online resources provided by the campaign. A majority of individuals indicated the need to mobilize and raise awareness for the problem of pain in dementia.

Lastly, the impact of the campaign on caregiver, health professional, and public knowledge and behaviour was also demonstrated. The results outlined on Table 2 display the impact of the short informational video on participants’ knowledge about the nature and problem of pain under-recognition and underassessment in dementia. Among all groups, mean ratings suggest that respondents had improved understanding for problem of pain in dementia as a result of watching the video. In addition, a majority of health professionals indicated willingness to recommend more systematic evaluation of non-verbal signs of pain after viewing the video. Moreover, more than half of members of the public indicated a greater understanding for the way pain may affect people with dementia after viewing the video. A majority of caregivers or family members of people with dementia also indicated that they were more likely to speak to a health professional about the presence responsive behaviours after watching the video. There were no significant differences among group types (i.e., caregivers, health professionals, and members of the public) on their responses relating to their impression on the use of social media for scientific dissemination, information-seeking behaviour, impression of the video, and level of new information provided. This could suggest that the short informational video was equally liked and beneficial among all respondents.

5.1 Directions for Future Research

Several limitations should be considered when interpreting the results of this study. First, a 5-
month evaluation period may not be sufficient to demonstrate the efficacy and sustainability of the messaging produced in the initiative. Future examinations should investigate potential changes in behaviours as a result of the content and messaging being disseminated for longer periods of time. In addition, changes in advocacy efforts (i.e., speaking to a health professional about responsive behaviours) for caregivers and frequency of pain assessment for health professionals before and after being exposed to the evidence-based information of the initiative could be explored. Furthermore, a short informational video and social media messaging were the main mediums used of disseminating evidence-based content. Future initiatives for pain in dementia could expand the type of content produced by incorporating shorter clips, images, and blog posts.

Paid advertisement was procured to expand the reach of the video on YouTube; as result, the number of total views may not be representative of the number of organic views. In addition, a limitation of the study is that the themes outlined were not validated by another independent source; as such, caution must be taken when interpreting the results and future examinations should establish consensual agreement to confirm the themes that emerged. Although this represents the first implementation and evaluation of a large-scale KT initiative for pain in dementia that gained tremendous traction, this effort was largely a grassroots initiative. Future developments could explore a science-media approach consistent with Chambers (2018) to reach broader audiences and scale production of evidence-based content. Moreover, interpretations on the effectiveness of the initiative in stimulating online discussions is limited to Twitter alone. Given the fast diffusion of content on social media, future investigations should evaluate the level of discussions in other prominent social media platforms. Lastly, the web-based nature and delivery of the study limits its standardization. Nevertheless, the study aimed to maximize reach
and potential impact by incorporating different methodologies (e.g., analytics, questionnaires, social listening) that would be constrained in an experimental KT design.

5.2 Conclusions

Untreated and undermanaged pain is costly and is associated with numerous deleterious consequences (Almeida et al., 2012; Choiniere et al., 2010; Jensen et al., 2011). This is compounded in LTC facilities where high rates of pain persist (Helme & Gibson, 2001). Although a large volume of research relating to pain assessment and management for older adults with dementia is available, gaps in current practices still exist. It takes an average of 17 years for research findings to be implemented into clinical practices (Morris, Wooding & Grant, 2011). Failure to translate research into tangible and beneficial outcomes has been identified as a factor for the estimated $200 Billion (USD) waste in research funding (Macleod et al., 2014). This is an unacceptable present state of affairs for older adults with dementia who continue to suffer from untreated pain. The scope, versatility, and utility of SM platforms creates numerous unique dissemination opportunities for health researchers.

The results from this investigation have implications in closing the knowledge to practice gap in dementia care. Findings from the study demonstrate the effectiveness of a social media KT initiative to diffuse evidence-based information and reach broader audiences. Moreover, the results demonstrate that the KT initiative was able to increase discussions and awareness for the problem of pain undertreatment in dementia. Social media KT initiatives can positively impact clinical practice, through increased pain assessments, improved pain management in people with dementia, and integration of consensus guidelines into front-line practices, by expediting the spread of evidence-based information and solutions to key stakeholders. Furthermore, capitalizing on the untapped potential of social media to mobilize scientific findings can allow
researchers to have immediate and direct impact in the lives of stakeholders around the world. Findings from this research could facilitate similar initiatives in other health disciplines. Finally, results from the study could contribute to the growing body of evidence for the use of social media and innovative methods to facilitate knowledge translation.
A majority of nurses, administrators, care aides and physicians indicated that clinical guidelines calling for at least weekly pain assessments, with timely treatment implementation and follow-up were helpful and feasible. They also indicated interest and willingness to use the recommendations in their practice.

Research suggests that with direction from a health professional, informal caregivers should be in a position to complete, in a valid fashion, standardized pain checklists (e.g., PACSLAC-II) for their loved ones.

Pain in severe dementia can be assessed effectively using validated observational checklists (e.g., PACSLAC-II). The PACSLAC scales have been translated and researched in several languages (e.g., Dutch, French, Japanese, Korean, Portuguese and Turkish).

**Figure 1.** Digital content samples from the #SeePainMoreClearly pain in dementia initiative. All content is available at [www.seepainmoreclearly.org](http://www.seepainmoreclearly.org). The short informational can be accessed through [https://youtu.be/9ONjQ7_ZvZA](https://youtu.be/9ONjQ7_ZvZA).
## Tables

**Table 1.** Participant characteristics of the video questionnaire respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>48.6 (16.5)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62 (88.6)</td>
</tr>
<tr>
<td>Male</td>
<td>8 (11.2)</td>
</tr>
<tr>
<td>Mode of locating the video</td>
<td></td>
</tr>
<tr>
<td>Facebook</td>
<td>23 (30.7)</td>
</tr>
<tr>
<td>Twitter</td>
<td>20 (26.7)</td>
</tr>
<tr>
<td>Family/friend</td>
<td>14 (18.7)</td>
</tr>
<tr>
<td>Website</td>
<td>6 (8.0)</td>
</tr>
<tr>
<td>YouTube</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (13.3)</td>
</tr>
<tr>
<td>Country</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>60 (85.7)</td>
</tr>
<tr>
<td>United States of America</td>
<td>5 (5.7)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (8.6)</td>
</tr>
<tr>
<td>Type of health professional</td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>6 (24.0)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>3 (12.0)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>3 (12.0)</td>
</tr>
<tr>
<td>Physician</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Front-line staff in long-term care facilities</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (32.0)</td>
</tr>
<tr>
<td>Relationship with the person with dementia</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>13 (52.0)</td>
</tr>
<tr>
<td>Parent</td>
<td>4 (16.0)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>4 (16.0)</td>
</tr>
<tr>
<td>Friend</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (8.0)</td>
</tr>
</tbody>
</table>

*Note.* Relationship with the person with dementia is based on responses of participants who identified as caregivers or family members of a person with dementia.
Table 2. The impact of the short informational video on self-reported knowledge about pain in dementia

<table>
<thead>
<tr>
<th></th>
<th>Caregiver</th>
<th>Health Professional</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Degree of knowledge about responsive</td>
<td>3.68 (1.95)</td>
<td>6.14 (1.36)</td>
<td>-</td>
</tr>
<tr>
<td>behaviours in dementia before watching the video(^a, e)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of knowledge about responsive</td>
<td>6.32 (1.11)</td>
<td>6.35 (1.19)</td>
<td>-</td>
</tr>
<tr>
<td>behaviours in dementia after watching the video(^b, e)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of knowledge about the problem</td>
<td>3.58 (1.98)</td>
<td>6.04 (1.40)</td>
<td>3.12 (2.10)</td>
</tr>
<tr>
<td>of pain under-recognition in dementia before watching the video(^c)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of knowledge of the problem of</td>
<td>5.68 (1.89)</td>
<td>5.70 (1.40)</td>
<td>6.15 (1.19)</td>
</tr>
<tr>
<td>pain under-recognition in dementia after watching the video(^d)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. N = 67. Ratings are based on a 7-point scale, where 1 = Not at all aware or Not at all to 7 = Very aware or Very much. a = Based on questions “before watching the video, did you ever consider responsive behaviours may be due to underrecognized or inadequately treated pain?” for caregivers and “before watching the video, did you ever consider that responsive behaviours may be due to underrecognized or inadequately treated pain?” for health professionals. b = Based on questions “after watching the video, how likely are you to talk to a health professional about the possibility that some responsive behaviours may be due to pain?” for caregivers and “after watching the video, are you more likely to recommend more regular and systematic evaluation of possible non-verbal signs of pain?” for health professionals. c = Based on questions “before watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?” for the public, “before watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?” for caregivers and “before watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?” for health professionals. d = Based on questions “after watching the video, do you have a better understanding of the way pain may affect people with dementia?” for the public, “after watching the video, do you have a better understanding of the way pain may affect people with dementia?” for caregivers and “after watching the video, did it encourage you to implement new approaches in your practice (e.g., use of standardized pain assessment checklists)?” for health professionals. e = questions that were not asked in the public group.
Table 3. Respondents’ overall impression on the short informational video

<table>
<thead>
<tr>
<th></th>
<th>Caregiver</th>
<th>Health Professional</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>The use of social media for scientific dissemination&lt;sup&gt;a&lt;/sup&gt;</td>
<td>6.32 (1.06)</td>
<td>5.91 (1.24)</td>
<td>6.48 (0.92)</td>
</tr>
<tr>
<td>Information-seeking behaviour&lt;sup&gt;b&lt;/sup&gt;</td>
<td>4.95 (2.25)</td>
<td>5.48 (1.62)</td>
<td>4.68 (1.84)</td>
</tr>
<tr>
<td>Overall impression of the video&lt;sup&gt;c&lt;/sup&gt;</td>
<td>5.63 (1.50)</td>
<td>6.35 (0.98)</td>
<td>6.31 (0.93)</td>
</tr>
<tr>
<td>Level of new information provided&lt;sup&gt;d&lt;/sup&gt;</td>
<td>5.53 (1.93)</td>
<td>5.78 (1.38)</td>
<td>5.88 (1.48)</td>
</tr>
</tbody>
</table>

<sup>Note.</sup> N = 67. a = Based on the question “It takes an average of 17 years until professionals start to use important research results into their practice. Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?” Ratings are based on a 7-point scale, where 1 = Not at all to 7 = Very much. b = Based on the question “Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video?” Ratings are based on a 7-point scale, where 1 = Not at all likely to 7 = Very much likely. c = Based on the question “Overall, how much did you like the video?” Ratings are based on a 7-point scale, where 1 = Not at all to 7 = Very much. d = Based on the question “Did the video provide you with new information?” Ratings are based on a 7-point scale, where 1 = Not at all to 7 = Very much.


Chambers, C. T. (2018). From evidence to influence: Dissemination and implementation of scientific knowledge for improved pain research and management. Pain, 159, S56-S64.


Lautenbacher, S. (2014). Pain assessment in special patient groups such as those with dementia: at the finishing line or just starting from scratch? *Pain*, 155(8), 1419-1420. Doi: 10.1016/j.pain.2014.05.001


APPENDIX

Pain in Dementia Video Evaluation Questionnaire

Please indicate a group that you belong in:

- Caregivers/family member/friend of person with dementia
- Person with dementia:
- Public
- Health Professional
- Policy Maker

Demographic Questions:

1. How did you find the video?
   - Facebook
   - Twitter
   - YouTube
   - Family/Friend
   - seepainmoreclearly website
   - if other, please describe: ______

2. Age: ______

3. Where are you from (country)?
   - Canada
   - United States of America
   - Other: _____

4. Gender:
   - Male
   - Female
   - Other: ____

5. Please specify your relationship with the person with dementia (e.g., Alzheimer’s Disease etc.)? *
   - Parent
   - Sibling
   - Child
   - Spouse
   - Grandparent
   - Relatives (Aunt, Uncle, Cousin)
   - Friend
   - Other (please specify): _______
6. What type of clinician/health care provider are you? **

- Nurse
- Physician (please indicate area of specialization, e.g., family medicine)
- Psychologist
- Physical Therapist
- Occupational Therapist
- Dentist
- Other Front-like staff in a nursing home/long-term care facility
- Other (please specify): _____

*only for family/caregivers. **only for health professionals
For the public

Part 1. Demographic questions

Part 2.

1. Overall, how much did you like the video? ***
   
   Not at all (0) ---- Very much (6)

2. Did the video provide you with new information? ***
   
   Not at all (0) ---- Very much (6)

3. BEFORE watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?
   
   Not at all aware (0) ------ Very aware (6)

4. AFTER watching the video, do you have a better understanding of the way pain may affect people with dementia?
   
   Not at all (0) ---- Very much (6)

5. Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video? ***
   
   Not at all likely (0) ---- Very much likely (6)

6. It takes an average of 17 years until professionals start to use important research results into their practice Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia? ***
   
   Not at all (0) --- Very much (6)

7. Are you going to follow the link with additional information that was provided at the end of the video? *
Yes, No, Unsure

8. **Would you/did you send the link to this video to other people? ***
   
   Yes, No, Unsure

**Part 3.**

1. Please provide any additional comments about the video: ______

2. If you are a family member, health professional of a person, or person with severe dementia who has suffered from unrecognized or untreated pain, we would love to hear your experience. Please share it below. __________

If you consent to sharing your story on our website (seepainmoreclearly.org), please leave your email below so we can contact you. These stories help increase the awareness of the undertreatment of pain in individuals with severe dementia.

Email: __________

Phone number (optional): _______

*** items present across all groups that will be analyzed in the one-way ANOVA
For caregivers/family member/friend of person with dementia

Part 1. Demographic questions:

Part 2.

1. Overall, how much did you like the video? ***
   
   Not at all (0) ---- Very much (6)

2. Did the video provide you with new information? ***
   
   Not at all (0) ---- Very much (6)

3. BEFORE watching the video, did you ever consider responsive behaviours (e.g., striking out, confusion, agitation) may be due to underrecognized or inadequately treated pain?
   
   Never (0) --- Very often (6)

4. BEFORE watching the video, how aware were you of the underassessment/underrecognition of pain in individuals with dementia
   
   Not at all aware (0) ------ Very aware (6)

5. AFTER watching the video, how likely are you to talk to a health professional about the possibility that some responsive behaviours (as shown in the video) may be due to pain?
   
   Not at all likely (0) ---- Very likely (6)

6. AFTER watching the video, do you have a better understanding of the way pain may affect people with dementia?
   
   Not at all (0) ---- Very much (6)

7. Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video? ***
Not at all likely (0) ---- Very much likely (6)

8. It takes an average of 17 years until professionals start to use important research results into their practice Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia? ***

Not at all (0) --- Very much (6)

9. Are you going to follow the link with additional information that was provided at the end of the video?

Yes, No, Unsure

10. Would you/did you send the link to this video to other people?

Yes, No, Unsure

Part 3.

1. Please provide any additional comments about the video: ______

2. If you are a family member, health professional of a person, or person with severe dementia who has suffered from unrecognized or untreated pain, we would love to hear your experience. Please share it below. __________

If you consent to sharing your story on our website (seepainmoreclearly.org), please leave your email below so we can contact you. These stories help increase the awareness of the undertreatment of pain in individuals with severe dementia.

Email: ____________
Phone number (optional): ______

*** ratings across all groups that will be analyzed through a one-way ANOVA
For person with dementia:

Part 1. Demographic questions

Part 2.

1. Please indicate how long you have been diagnosed with dementia: ____

2. Overall, how much did you like the video?
   Not at all (0) ---- Very much (6)

3. Did the video provide you with new information?
   Not at all (0) ---- Very much (6)

4. BEFORE watching the video, did you consider discussing the issue of pain in dementia with your loved ones and/or health professionals?
   Not at all (0) ---- Very much (6)

5. BEFORE watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?
   Not at all aware (0) ------ Very aware (6)

6. AFTER watching the video, would you consider discussing the issue of pain in dementia with your loved ones and/or health professionals?
   Not at all (0) ---- Very much (6)

7. AFTER watching the video, do you have a better understanding of the way pain may affect people with dementia?
   Not at all (0) ---- Very much (6)

8. Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video?
   Not at all likely (0) ---- Very much likely (6)
9. It takes an average of 17 years until professionals start to use important research results into their practice. Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?

   Not at all (0) --- Very much (6)

10. Are you going to follow the link with additional information that was provided at the end of the video?

   Yes, No, Unsure

11. Would you/did you send the link to this video to other people?

   Yes, No, Unsure

Part 3.

1. Please provide any additional comments about the video: ________

2. If you are a family member, health professional of a person, or person with severe dementia who has suffered from unrecognized or untreated pain, we would love to hear your experience. Please share it below. ____________

If you consent to sharing your story on our website (seepainmoreclearly.org), please leave your email below so we can contact you. These stories help increase the awareness of the undertreatment of pain in individuals with severe dementia.

   Email: ____________
   Phone number (optional): ________
For health professionals

Part 1. Demographic questions:

Part 2.

1. Overall, how much did you like the video?
   Not at all (0) ---- Very much (6)

2. How relevant was this video in your own practice?
   Not at all relevant (0) ---- Very relevant (6)

3. Did the video provide you with new information?
   Not at all (0) ---- Very much (6)

4. BEFORE watching the video, did you ever consider that responsive behaviours (e.g., striking out, agitation, confusion) may be due to underrecognized or inadequately treated pain?
   Never (0) --- Very often (6)

5. BEFORE watching the video, how aware were you of the underassessment/underrecognition of pain in individuals with dementia?
   Not at all aware (0) ------ Very aware (6)

6. AFTER watching the video, are you more likely to recommend more regular and systematic evaluation of possible non-verbal signs of pain?
   Not at all (0) ---- Very much (6)

7. AFTER watching the video, did it encourage you to implement new approaches in your practice (e.g., use of standardized pain assessment checklists)?
   Not at all (0) ---- Very much (6)
12. Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video?

   Not at all likely (0) ---- Very much likely (6)

13. It takes an average of 17 years until professionals start to use important research results into their practice Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?

   Not at all (0) --- Very much (6)

14. Are you going to follow the link with additional information that was provided at the end of the video?

   Yes, No, Unsure

15. Would you/did you send the link to this video to other people?

   Yes, No, Unsure

Part 3.
1. Please provide any additional comments about the video: __________

2. If you are a family member, health professional of a person, or person with severe dementia who has suffered from unrecognized or untreated pain, we would love to hear your experience. Please share it below. __________

If you consent to sharing your story on our website (seepainmoreclearly.org), please leave your email below so we can contact you. These stories help increase the awareness of the undertreatment of pain in individuals with severe dementia.

   Email: __________
   Phone number (optional): ______
For policy makers:

**Part 1. Demographic questions:**

**Part 2.**

1. Please describe the nature of your involvement in policy development and implementation: __________

2. Overall, how much did you like the video?
   
   Not at all (0) ---- Very much (6)

3. Did the video provide you with new information?
   
   Not at all (0) ---- Very much (6)

4. **BEFORE** watching the video, how aware were you of the underassessment/under-recognition of pain in individuals with dementia?
   
   Not at all aware (0) ------ Very aware (6)

5. **AFTER** watching the video, do you think that there is a need for policy change to help ensure that pain is assessed adequately in long term care (LTC) facilities?
   
   Not at all (0) ---- Very much (6)
   
   Please explain: _____

6. Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video?
   
   Not at all likely (0) ---- Very much likely (6)

7. It takes an average of 17 years until professionals start to use important research results into their practice  Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?
8. Are you going to follow the link with additional information that was provided at the end of the video?
   Yes, No, Unsure

9. Would you/did you send the link to this video to other people?
   Yes, No, Unsure

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