

# The Effectiveness of Social Media in the Dissemination of Knowledge About Pain in Dementia

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## Abstract

**Objectives.** Traditional knowledge dissemination methods have been ineffective in leading to timely and widespread changes in clinical practice. Social media have the potential to reach broader audiences than more traditional methods that disseminate research findings. We evaluated the effectiveness of using social media to mobilize knowledge about pain in dementia. **Methods.** We developed an online repository of evidence-based content (e.g., guidelines, assessment approaches) and a video about pain in dementia. The video was uploaded to YouTube, a video-sharing platform. We collaborated with stakeholder organizations on a 5-month social media campaign (#SeePainMoreClearly) on Twitter, a social networking site, to disseminate digital content about pain in dementia. The response to our initiatives was evaluated with Web and social media metrics, a video questionnaire, and a comparison of the extent of Twitter discussions about pain in dementia before and during the campaign period. **Results.** Web metrics showed a great reach of the initiative: The #SeePainMoreClearly hashtag received more than 5,000,000 impressions and was used in 31 countries. The online repository was viewed by 1,218 individuals from 55 countries, and the video resulted in 51,000 views. Comparisons between the pre-campaign and campaign periods demonstrated a higher number of posts about pain in dementia during the campaign period. **Conclusion.** The findings have implications for closing the knowledge-to-practice gap in dementia care through faster mobilization of scientific findings. Our campaign compares favorably with other health information dissemination initiatives. The methodologies used in the study could serve as a framework for the development of social media initiatives in other health disciplines.

**Key Words:** Elderly; Alzheimer's Disease; Older Adults; Knowledge Translation; Knowledge Mobilization

## Introduction

Although thousands of scientific articles are produced each year, significant barriers prevent their findings from being translated into widespread changes in clinical practice [1–4]. These barriers include resource limitations and difficulties in disseminating the research knowledge to clinical front lines [2]. Given the

challenges of moving research into practice, there is an increasing emphasis on mobilizing available evidence-based information. Knowledge mobilization incorporates knowledge dissemination and encompasses a wide range of activities aimed at the transfer and exchange of information between researchers and knowledge users [5].

## Pain in Dementia

Despite the availability of evidence-based methods for evaluating and managing pain in people with dementia, clinical practice lags behind the research, and pain tends to be underassessed and undertreated in this population [6–9]. It is estimated that as many as 80% of long-term care residents with dementia suffer from pain [10]. Moreover, cognitive impairments associated with severe dementia compromise residents' ability to effectively communicate their pain experience [11,12]. As such, a large body of research has examined and validated the use of observational pain assessment tools to assess nonverbal pain cues in this population [13,14]. Regular use of these tools has been shown to improve pain management practices and reduce nursing staff stress in long-term care settings [15,16]. This area of research has led to a substantial body of knowledge that has been summarized in literature reviews [14,17,18] and in clinical guidelines adopted by influential organizations such as the British Geriatrics Society [19], a task force of the American Society for Pain Management Nursing [20], the National Nursing Home Pain Collaborative [11], and the American Medical Directors Association [21]. Nonetheless, these guidelines and this knowledge base have not been widely implemented on the clinical front lines, resulting in the continuing problem of pain underrecognition and undermanagement in this population [6–9].

## Social Media as a Dissemination Strategy

Traditional knowledge dissemination methods (e.g., workshops, brochures) have had limited success in changing clinical practice in a timely manner [22]. For instance, it can take an average of 17 years for research results to find their way into widespread clinical practice [23,24]. Social media platforms have become influential in shaping public opinion and reaching large numbers of people in a very short time [25,26]. Harnessing the power of social media could allow us to overcome the inefficiencies and limited reach of more traditional knowledge dissemination approaches. Efforts involving the use of social media to disseminate evidence-based health information have shown that social media platforms present unique opportunities to share relevant information with key stakeholders [27–29]. Key stakeholder groups, such as caregivers and patients, are increasingly turning to social media to access and share health information [30,31].

Researchers have used Web-based knowledge mobilization methods by creating online repositories (e.g., [32]) and brief educational videos (e.g., [33–35]) and by disseminating information through social media (i.e., Facebook, Twitter, Instagram) (e.g., [29,36]). Chambers' [36] “#ItDoesntHavetoHurt” social media initiative in pediatric pain had worldwide impact and great success in producing and disseminating digital evidence-based content tailored to the needs of parents and health

professionals. The initiative also resulted in beneficial changes to parent behaviors [36].

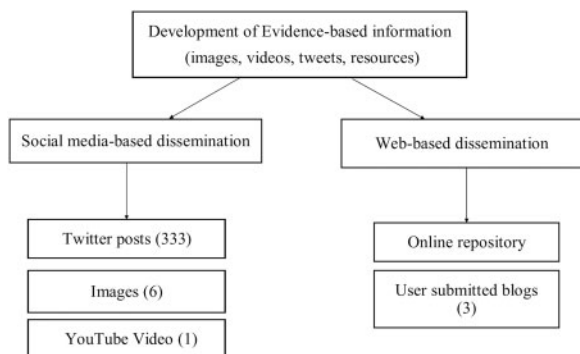
## The #SeePainMoreClearly Campaign

Our social media campaign (#SeePainMoreClearly) aimed to raise awareness of problems and solutions related to pain in dementia. Our hashtag was created to optimize user engagement and was vetted by various stakeholder organizations (e.g., dementia support organizations) and individuals (e.g., caregivers and health professionals) to ensure that the hashtag captured our intended message. Our initiative was directed to health professionals, caregivers, and health policy makers. Some of our approaches followed those previously used by Chambers and colleagues in a pediatric context [32,33,36]. Moreover, older adults were a target audience for our dissemination strategy, a population that is generally well equipped to adopt social media-based knowledge [37]. The primary purpose of the study was to develop and evaluate Web- and social media-based knowledge dissemination approaches to share evidence-based information about pain in dementia. The specific aims of the study were to: 1) increase awareness and discussions about the problem of pain in dementia by developing an online repository of evidence-based content and by initiating a Twitter awareness campaign, and 2) examine the reach of an engaging short 2-minute video in raising stakeholder awareness of information related to pain in dementia. To accomplish these goals, we used: 1) Web/social media metrics, 2) a comparison of Twitter discussions about pain in dementia between the campaign and a control period, 3) a qualitative analysis of all the tweets that used the #seepainmoreclearly hashtag, and 4) video views and a video evaluation questionnaire. We anticipated that: 1) a social media campaign would reach large numbers of users both inside and outside of Canada; 2) Web analytics would demonstrate frequent visits to our online resource repository; 3) there would be an increase in online discussions about pain in dementia compared with a control pre-campaign period; and 4) our short 2-minute video would accumulate a large number of views, would be rated favorably by stakeholders, and would increase their awareness of issues related to pain in dementia.

## Methods

### Development

Our development strategy involved a Web-based dissemination approach (i.e., online repository), a Twitter social media campaign, and a short informational video posted to YouTube (see Figure 1). Health care professionals (e.g., nurses), caregiver partners, and organizations (e.g., Canadian Association on Gerontology, AGE-WELL Network of Centres of Excellence, Canadian Institutes of Health Research Chronic Pain Network, and Alzheimer



**Figure 1.** Dissemination strategy. Number of Twitter posts reflect the total number of posts made during the initiative using the #SeePainMoreClearly hashtag on the two Twitter accounts used for the project.

Society of Saskatchewan) were involved in supporting our social media strategy and in disseminating the evidence-based content. Communication with partners was sustained through in-person/telephone/online meetings and by email.

### Online Repository

An online repository ([www.seepainmoreclearly.org/resources](http://www.seepainmoreclearly.org/resources)) was developed from evidence-based information derived from the scientific literature and included material on the prevalence and underassessment of pain in dementia [8,15,16] and guidelines for clinical management [13,17,18]. The repository also included information about standardized and validated observational pain assessment tools for people with severe dementia (e.g., [38]). A story submission page that invited website visitors (e.g., informal caregivers and clinicians) to share their personal experiences with pain and dementia was also part of the website. These stories were published as blog posts on the website after appropriate consent had been obtained.

### #SeePainMoreClearly Campaign

We disseminated scientific information by using engaging and accessible digital content. Figure 2 includes examples of evidence-based content produced during the initiative. Our content was disseminated throughout the campaign. Two Twitter accounts were used as starting points for the dissemination effort (@UofRAGINGCentre and @URHealthPsycLab). An example of a post disseminated on Twitter was: “Pain in seniors with dementia is often underassessed and undertreated. We are trying to raise awareness of this problem and to spread the word about evidence-based solutions through <http://seepainmoreclearly.org> #SeePainMoreClearly.” The campaign was launched on October 1, 2019, the International Day of Older Persons. To increase the reach of our campaign, we used Twitter’s paid promotion (i.e., an approximate total of \$390.00 CAD) feature for one month. Moreover, we worked with our caregiver and organization partners

to plan scheduled tweets and encouraged partners to retweet content produced by the research team.

### Short Informational Video

We created an engaging 2-minute video to relay information about the problem of pain in dementia in an easily accessible and understandable format. The research team began by preparing a video script based on research evidence about pain in dementia. Next, the team modified the content with input from stakeholder partners, including health professionals, caregivers, advocacy groups, and research organizations. We then worked with a video production company to create the video with actors cast for specific roles. The video was filmed at a local long-term care facility, and the final product was uploaded to YouTube with the title “Pain in Dementia #SeePainMoreClearly” ([https://youtu.be/9ONjQ7\\_ZvZA](https://youtu.be/9ONjQ7_ZvZA)).

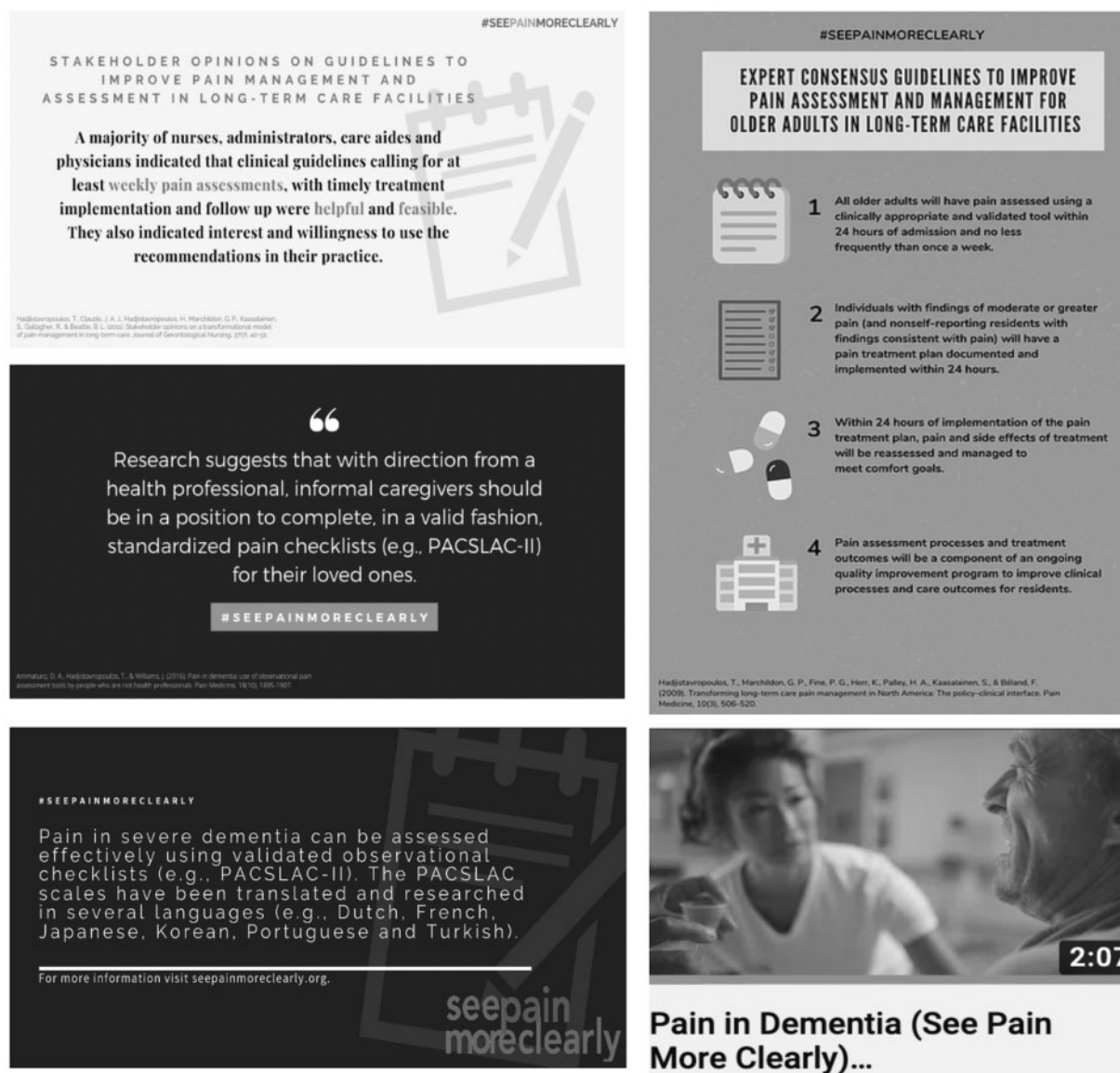
The video depicts an older adult with severe dementia who is showing responsive behaviors (e.g., agitation) and well-intentioned nursing staff initially misattributing the responsive behaviors to causes other than pain. The next scene shows the same older adult at an earlier stage of his life telling the audience that he had just received a diagnosis of Alzheimer’s disease. He then offers guidance to his future caregivers, from his perspective, on how to better understand any pain he might experience. In the final scene, the same nursing staff members are shown successfully recognizing and managing his pain. Paid promotions (i.e., a total of \$540.00 CAD) through Google/YouTube were used for a one-month period in order to maximize the reach of the video.

### Evaluation

#### Online Resource Repository and Social Media Campaign Analytics

A longitudinal data collection strategy was used to obtain Web and social media metrics over the 5-month (i.e., October 1, 2019, to February 28, 2020) campaign period. The reach, scope, and engagement of the initiative and Web-based repository were monitored through social media metrics (e.g., Web analytics, hashtag analytics, Twitter analytics). Similar metrics have been used in previous research to quantify the impact of social media initiatives and online resources [32,36]. The Keyhole social media monitoring Web-based platform [39], which has been used effectively in previous investigations [40–42], allowed us to extract social media metrics and analytics. Keyhole tracks metrics (e.g., mentions, impressions/views, total number of posts, number of individuals who used a specified hashtag) for any specified hashtag, keyword, or Twitter account.

To evaluate our Twitter initiative, the number of impressions (i.e., the number of times users have seen the online content), reach (i.e., the number of unique users who have seen the online content), engagement (i.e., the



**Figure 2.** 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 video can be accessed through [https://youtu.be/9ONjQ7\\_ZvZA](https://youtu.be/9ONjQ7_ZvZA).

number of retweets and “likes”), and posts using the #SeePainMoreClearly hashtag were recorded using the Keyhole Web-based platform [39]. Keyhole was also used to collect demographic information (e.g., gender, country) of the Twitter users that engaged with our content. The number of mass media (e.g., newspaper, television, magazine) stories focusing on the campaign were tracked as evidence of impact. For the Web-based repository, the number of content viewers were tracked using Google Analytics [43].

### Social Media Posts About the Campaign

Social media posts (i.e., tweets) from users who used the hashtag or responded to our messaging and content posted on Twitter were subjected to a content analysis. Retweet posts (i.e., non-original tweets or containing

“RT”) were omitted from the analysis, and only the tweets that were not generated by our research team were considered. NVivo (Version 12) software [44] was used to facilitate the qualitative content analysis. In line with this approach, the data were broken down into meaning units, and themes emerged from the textual data [45]. Our aim was to understand the types of tweets (i.e., opinion, personal experiences, information) shared with the hashtag to determine prevalent themes [45]. After the meaning units were determined, 15% percent of the data were randomly selected and examined to develop a coding book. The development of the coding scheme was based on literature precedent (e.g., developing a coding book by examining a portion of all the tweets) [46,47] and saturation (i.e., no new codes were being generated with the examination of additional data). Two independent coders individually coded the textual data. The



**Table 1.** Themes and examples of tweets using the #SeePainMoreClearly hashtag or in response to the content produced during the initiative

Theme	Example
Information and Resources	<p>“More than half a million Canadians are living with #dementia, and about 25,000 new cases are diagnosed each year.”</p> <p>“@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. <a href="https://t.co/FzyPyEJDLo">https://t.co/FzyPyEJDLo</a> #IDOP2019 #UNIDOP @UofRAgingCentre #SeePainMoreClearly”</p> <p>“Launched by @AGEWELL_NCE, #seepainmoreclearly campaign helps the public and #healthcare community understand the importance of treating pain in those living with #Dementia <a href="https://t.co/q7C1emE84Q">https://t.co/q7C1emE84Q</a> <a href="https://t.co/DqsKxd5yQB">https://t.co/DqsKxd5yQB</a>”</p>
Expressions of Support	<p>“This is brilliant. Well done.”</p> <p>“It is my great pleasure to support the @URHealthPsycLab social media campaign to disseminate information about pain in #dementia. Watch their video to help spread the word and find solutions <a href="https://t.co/8hWVMDAC0r">https://t.co/8hWVMDAC0r</a> #SeePainMoreClearly Please consider retweeting. #Alzheimers”</p> <p>“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”</p>
Advocacy for Better Care	<p>“We have to ensure we spread this message #assessment #pain#dementia”</p> <p>“People living with dementia should not have to endure chronic pain”</p> <p>“Awareness of identifying the signs of pain needs to be a priority for healthcare professionals and carers”</p>
Expressions of Opinion or Commentary	<p>“People with severe #dementia often suffer from #pain in isolation.”</p> <p>“Your words will help others w/similar challenges. #pain #seepainmoreclearly”</p> <p>“I imagine many will have an ‘unrecognized pain in dementia’ story.”</p>
Personal Experiences	<p>“These evidence-based #pain #assessment &amp; #management strategies could have eased suffering for our parents w/#Alzheimers. #SeePainMoreClearly #caregiving”</p> <p>“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.”</p> <p>“Over the 61 days in ACF ..0.53 days antipsychotics, 30 days epilim , 10 days of multiple benzos but on only 9 days Mum received paracetamol. And even then, Paracetamol was less than recommended geriatric dose #seepainmoreclearly”</p>
Other	<p>“#SeePainMoreClearly”</p>

development of the coding book and coding of meaning units were discussed by members of the research team to refine categories and discuss discrepancies. Discrepancies that resulted from disagreements were clarified and resolved. As an example of a disagreement/error, the meaning unit “*As past caregiver, I can’t over stress need for effective #pain #assessment & #management in #dementia*” was initially coded under the Information and Resources category but was later recategorized as Personal Experiences after a discussion between the two coders. In addition, the meaning unit “*Read more about a new social media campaign aiming to raise awareness of pain in people with dementia.* <https://t.co/shpsnJrXFT>” was coded as Expressions of Support but after discussion was recategorized under Information and Resources. The finalized coding book consisting of the themes that emerged from that data is outlined in Table 1.

In qualitative research, certain elements (i.e., credibility, dependability, transferability) must be considered in order to establish the trustworthiness of the results [45]. To establish trustworthiness, the coding for a randomly selected 15% of the textual data was examined and completed by two independent coders. A comparison between the two coders indicated a 95% coding agreement. Using Twitter data also allowed us to collect a breadth of information from various stakeholders (e.g., health care

professionals, researchers, caregivers) that may have been inaccessible through traditional recruitment methods or in-person interviews. The credibility of our research findings was also established by conducting qualitative consistency checks on the coded themes and categories, discussing discrepancies between coders, and communicating throughout the process until an agreement was reached. Moreover, we used a stable and consistent approach to maximize the dependability of the results. To facilitate the transferability of our findings, we outlined our data analysis strategy and representative quotations of each theme (Table 1). It is important to note that, because we examined responses to a specific hashtag (#SeePainMoreClearly), our results and interpretations are limited to the #SeePainMoreClearly initiative.

#### Social Media Discussions: Control Period vs Campaign Period

We established two periods of comparison for the Keyhole data: 1) a pre-campaign control period (October 1, 2018, to February 28, 2019) and 2) a campaign period (October 1, 2019, to February 28, 2020). Searches for tweets containing the hashtags #pain #dementia AND/OR key words *pain dementia* were conducted for the pre-campaign and campaign periods. We then compared

**Table 2.** Intercorrelations of video questionnaire items

		1	2	3	4	5	6	7
Public	1. Using social media for scientific dissemination	1.000						
	2. Impact on information-seeking behavior	0.241	1.000					
	3. Overall impression of the video	0.661	0.127	1.000				
	4. Level of new information provided	0.484	0.314	0.451	1.000			
	5. Degree of awareness for the problem of pain in dementia	0.550	0.376	0.450	0.942	1.000		
Caregivers	1. Using social media for scientific dissemination	1.000						
	2. Impact on information-seeking behavior	-0.160	1.000					
	3. Overall impression of the video	0.218	0.769	1.000				
	4. Level of new information provided	-0.004	0.726	0.822	1.000			
	5. Likelihood of speaking to a health professional about behaviors relating to pain	0.100	0.297	0.375	0.152	1.000		
	6. Improved understanding about pain	-0.031	0.677	0.782	0.966	0.103	1.000	
Health Care Professionals	1. Using social media for scientific dissemination	1.000						
	2. Impact on information-seeking behavior	0.293	1.000					
	3. Overall impression of the video	0.175	0.662	1.000				
	4. Level of new information provided	0.270	0.138	0.453	1.000			
	5. Relevance of video to their practice	0.227	0.699	0.628	-0.023	1.000		
	6. Likelihood of recommending regular evaluation of pain	0.268	0.405	0.669	0.551	0.352	1.000	
	7. Likelihood of using pain assessment checklists	0.273	0.590	0.744	0.419	0.530	0.559	1.000

the mean number of tweets posted each month for these two periods.

**Video Evaluation**

The video was launched concurrently with the Twitter media initiative. Video views and analytics were tracked to evaluate the video over a 5-month period. Consistent with the program evaluation process of survey development [48], a short evaluation questionnaire was created for the purposes of soliciting anonymous responses from various stakeholders. The questionnaire was uploaded to the Qualtrics platform[49], and a link was provided for viewers below the video. The survey included both general and specific questions for the general public, health professionals, and caregivers/family of people with dementia. The number of questions varied (from 8 to 15) as a function of the group with which the content viewers identified. Most responses were provided along seven-point Likert scales (e.g., 1 = not very likely to 7 = very likely) and focused on viewers’ opinions about the short informational video and the likelihood that viewers would use the information provided in the video. In addition, the questionnaire included open-ended requests, such as “Please provide any additional comments on the video.” Finally, the survey contained questions about the respondent’s age, gender, country, and occupation. The internal consistency of the questionnaire was satisfactory for the caregiver group (Cronbach’s alpha = 0.830), health professional group (Cronbach’s alpha = 0.813), and general public (Cronbach’s alpha = 0.768). To

capture the underlying construct of a viewer’s impression on the video and video content, items that assessed the degree of prior knowledge about the information discussed in the video were excluded from the internal consistency calculation. The correlations of the items included in the internal consistency analyses are shown in Table 2. Descriptive statistics were used to calculate means and standard deviations for the Likert scale items in the evaluation questionnaire. Demographic characteristics were also summarized with descriptive statistics.

Open-ended questions were subjected to a content analysis. A total of 34 responses were examined. A coder initially identified the meaning units within each response. Some responses contained more than one meaning unit; therefore, to assess agreement in the determination of the meaning units, a second independent coder identified the meaning units within a randomly selected 15% of the responses. The two coders showed complete agreement. The thematic analytic approach and development of the coding book were similar to the approach outlined in the “Social Media Posts About the Campaign” section above.

**Results**

**Online Repository and Social Media Campaign Web and Social Media Metrics**

The social media metrics for a 5-month campaign period from October 1, 2019, to February 28, 2020, were tracked. The hashtag #SeePainMoreClearly garnered

5,748,917 Twitter impressions, representing a hashtag “reach” of 2,376,853 unique users who had seen or interacted with the hashtag (e.g., tweeted or retweeted messages containing the hashtag). Moreover, a total of 2,905 posts (75% retweets, 16.15% original tweets, and 8.43% reply tweets) were shared during this period with the hashtag by 578 individuals, 86.9% of whom were female. Chi-squared analysis confirmed the gender difference in the proportions of individuals who tweeted about the campaign; most Twitter users were female ( $\chi^2(1) = 362.913, P < 0.01$ ). In terms of user location, our hashtag was used in 31 countries, with 20% of the interactions occurring in countries outside of Canada. Sixty-eight percent of the hashtag users used mobile phones to engage with the initiative on Twitter. The seepainmoreclearly.org online repository of resources and information was also tracked for the 5-month period. The website was viewed 5,751 times by 1,218 unique individuals (54% male, 46% female) in 55 countries.

### Media Stories About the Campaign

The number of media stories was tracked throughout the campaign as evidence of impact. Among the 10 media stories that covered the initiative, five were recorded interviews (i.e., Canadian Broadcasting Corporation [CBC] Saskatchewan, CTV Regina Live, CBC Radio, 620 CKRM, and Global News 770 CHQR Radio Calgary) and five were written interviews/stories (i.e., Leader Post, Discourse Magazine, Relief Magazine, Canadian Institutes of Health Research, Dementia Connections).

### Qualitative Analysis of Social Media Posts About the Campaign

The textual data that were subjected to qualitative analysis consisted of tweets with the #SeePainMoreClearly hashtag and responses to tweets shared by our team during the initiative. The six themes that emerged through the qualitative analysis were 1) Information and Resources, 2) Expressions of Support, 3) Advocacy for Better Care, 4) Expressions of Opinion or Commentary, 5) Personal Experiences, and 6) Other. A summary of the themes and examples of tweets that fell under each of these themes are outlined in Table 1.

A majority of the tweets contained details about the initiative, the topic of pain in dementia, or other related matters. These tweets were classified under the Information and Resources theme. Most of these tweets included a link to seepainmoreclearly.org or another external resource, news stories about the initiative, and content disseminated during the initiative (e.g., a person tweeted: “It is my great pleasure to support the @URHealthPsycLab social media campaign to disseminate information about pain in #dementia. Watch their video to help spread the word and find solutions <https://t.co/8hWVMDAC0r> #SeePainMoreClearly Please

consider retweeting. #Alzheimers”). As such, several tweets that included information and resources also expressed support for the initiative. See Table 1 for examples of meaning units for the Information and Resources theme.

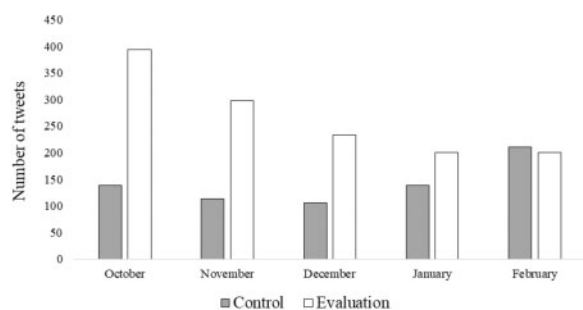
The second most frequent theme that emerged from the data captured Expressions of Support. Several tweets encouraged others to retweet or share the content disseminated during the initiative, including links to news stories, websites, or other content related to the initiative. In addition, people showing support also provided positive comments about the initiative or content shared (e.g., a person tweeted: “Great video!”). Many knowledge users that showed support for the initiative indicated that the campaign raised awareness of an important issue and the need to mobilize available solutions (see Table 1).

The third theme that emerge from the textual data involved Advocacy for Better Care. Unlike the other themes that emerged from the data, a majority of responses within this category highlighted deficiencies in current practices and outlined the need to improve care for individuals with dementia (e.g., a person tweeted: “We need to do better”).

Another prevalent theme reflected Expressions of Opinion or Commentary. These were tweets that provided responses without sharing resources, showing support for the campaign, or advocating for improved care (e.g., “dementia patients are suffering in silence”). In addition, a majority of these tweets were in response to conversations among individuals (e.g., “I agree with you!”). As shown in Table 1, tweets also outlined direct Personal Experiences (e.g., as a health professional, caregiver, person with dementia, or researcher) or indirect experiences of a loved one (e.g., family member or friend) with regard to pain in dementia. Finally, a small proportion of tweets contained information that did not fit with any of the other prevalent themes. These were tweets containing only the hashtag or user mentions (e.g., @Name) without context.

### Comparison Between the Control and Campaign Periods

Tweets about pain in dementia including keywords “pain dementia” or “#pain #dementia” were individually examined. The following types of tweets were excluded: 1) retweets or tweets including “RT”; 2) tweets pertaining to pain as a metaphor (i.e., using “pain” as a metaphor for psychological distress, such as in the context of grief: “I feel your pain”) or tweets unrelated to the problem of pain in dementia; and 3) tweets shared by our own research group ( $n = 210$ ). Figure 3 presents the number of tweets posted each month over the two periods. During the pre-campaign control period (i.e., October 1, 2018, to February 28, 2019), a total of 707 tweets about pain in dementia were posted, as compared with 1,325 tweets during the campaign period (i.e., October 1, 2019, to February 28, 2020). A comparison between the two



**Figure 3.** Total number of tweets about pain in dementia per month. Control period= October 1, 2018, to February 28, 2019. Evaluation/campaign period= October 1, 2019, to February 28, 2020.

periods indicated that the number of pertinent tweets was significantly higher during the campaign period (mean [M]=265.20/month; standard deviation [SD] 82.27) than during the control period (M=141.40/per month; SD=41.60),  $t(8) = 3.00, P = 0.017$ . That is, there were approximately twice as many pertinent tweets per month during the campaign period than in the pre-campaign period.

### Short Informational Video

#### Video Analytics

Over a 5-month period, the campaign video was viewed 50,880 times, received 172 “likes,” and garnered more than 150,578 impressions on YouTube. The video views reflected 48,861 unique users, of whom 64% were male and 36% were female, which represents a statistically significant gender difference ( $\chi^2(1) = 3830.658, P < 0.01$ ). Fifty-one percent of the viewers were between the ages of 18 and 44, 33% were in the 45 to 64 age group, and 16% of the viewers were more than 65 years of age.

#### Questionnaire Responses

A relatively small number of YouTube viewers (n=83) responded to our video evaluation questionnaire, and 80.7% of those respondents answered all the questions. Respondent characteristics are outlined in Table 3. Most respondents were female ( $\chi^2(1) = 41.657, P < 0.01$ ), Facebook was the most frequent mode of locating the video ( $\chi^2(5) = 26.200, P < 0.01$ ), most of the viewers were from Canada ( $\chi^2(2) = 86.514, P < 0.01$ ), and of those who were caregivers, most were children of the person with dementia ( $\chi^2(4) = 16.800, P = 0.002$ ).

The impact of the informational video on self-reported knowledge about pain in dementia is outlined in Table 4. Among the respondents, 28.4% were caregivers or family members of a person with dementia, 34.3% were health professionals, and 37.3% were members of the public. A majority of respondents reported a greater understanding of the way pain may affect people with dementia as a result of viewing the video. Members of the public, for example, reported increased awareness of the

**Table 3.** Participant characteristics of the video questionnaire respondents

	(%)
Mean age in years (SD)	48.6 (16.4)
Gender	
Female	88.6
Male	11.2
Mode of locating the video	
Facebook	30.7
Twitter	26.7
Family/friend	18.7
Website	8.0
YouTube	2.7
Other	13.3
Country	
Canada	85.7
United States of America	5.7
Other	8.6
Type of health care professional	
Nurse	24.0
Occupational therapist	12.0
Psychologist	12.0
Physician	4.0
Front-line staff in long-term care facilities	8.0
Other	32.0
Relationship with the person with dementia	
Child	52.0
Parent	16.0
Grandparent	16.0
Friend	8.0
Other	8.0

*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.

problem of pain in dementia after viewing the video. A majority of health professionals expressed willingness to recommend more systematic evaluations of nonverbal pain behaviors after viewing the video. Finally, a majority of caregivers or family members of people with dementia indicated that they were more likely to speak to a health professional about the presence of responsive behaviors (that may be related to pain) as a result of watching the video. Fifty-two percent of the respondents reported that they followed the link to our seepainmoreclearly.org website after viewing the video, and 74.6% expressed strong willingness to send the video to others.

#### Comparisons by Respondent Background

A summary of responses on the use of social media for mobilization of scientific knowledge, information-seeking behavior, impressions of the video, and level of new information provided is outlined in Table 5. To explore the possibility of response differences as a function of respondent background (i.e., health professionals, public, and caregivers), four one-way analyses of variance (ANOVAs) were conducted. The results (Table 5) indicated no significant group differences with regard to the following: views on the use of social media for scientific dissemination ( $F(2, 64) = 1.729, P = 0.186, \eta^2 = 0.05, M = 6.24, SD = 1.09$ ),



**Table 4.** The impact of the short informational video on self-reported knowledge about pain in dementia

	Mean (SD)
<b>Prior knowledge about pain in dementia</b>	
Public	
Degree of awareness for the problem of pain under-assessment in dementia <i>before</i> watching the video <sup>a</sup>	3.12 (2.10)
Health care professional	
Considered that responsive behaviors in dementia may be due to pain <i>before</i> watching the video <sup>c</sup>	6.14 (1.36)
Degree of awareness for the problem of pain underassessment in dementia <i>before</i> watching the video <sup>a</sup>	6.04 (1.40)
Caregivers	
Considered that responsive behaviors in dementia may be due to pain <i>before</i> watching the video <sup>c</sup>	3.68 (1.95)
Degree of awareness for the problem of pain underassessment in dementia <i>before</i> watching the video <sup>a</sup>	3.58 (1.98)
<b>Knowledge about pain in dementia</b>	
Public	
Degree of awareness for the problem of pain underassessment in dementia <i>after</i> watching the video <sup>b</sup>	6.15 (1.19)
Health care Professional	
Relevance of video to their practice <sup>b</sup>	5.78 (1.38)
Likelihood of recommending regular evaluation of nonverbal signs of pain <i>after</i> watching the video <sup>b</sup>	6.35 (1.19)
Likelihood of using standardized pain assessment checklists <i>after</i> watching the video <sup>b</sup>	5.70 (1.40)
Caregivers	
Likelihood of speaking to a health professional about the presence of responsive behaviors relating to pain <i>after</i> watching the video <sup>d</sup>	6.32 (1.11)
Improved understanding for the way pain may affect people with dementia <i>after</i> watching the video <sup>b</sup>	5.68 (1.89)

Note: Ratings are based on a seven-point scale: a = 1 (not at all aware) to 7 (very aware); b = 1 (not at all) to 7 (very much); c = 1 (never) to 7 (very often); d = 1 (not at all likely) to 7 (very likely).

**Table 5.** Respondents' overall impression on the short informational video

	Caregiver	Health Care Professional	Public
	Mean (SD)	Mean (SD)	Mean (SD)
Using social media for scientific dissemination <sup>a</sup>	6.32 (1.06)	5.91 (1.24)	6.48 (0.92)
Impact on information-seeking behavior <sup>b</sup>	4.95 (2.25)	5.48 (1.62)	4.68 (1.84)
Overall impression of the video <sup>c</sup>	5.63 (1.50)	6.35 (0.98)	6.28 (0.94)
Level of new information provided <sup>d</sup>	5.53 (1.93)	5.78 (1.38)	5.84 (1.49)

Note: 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 seven-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 seven-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 seven-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 seven-point scale, where 1 = not at all to 7 = very much.

impact on information-seeking behavior ( $F(2, 64) = 1.087$ ,  $P = 0.344$ ,  $\eta^2 = 0.03$ ,  $M = 5.03$ ,  $SD = 1.90$ ), overall impression of the video ( $F(2, 64) = 2.464$ ,  $P = 0.093$ ,  $\eta^2 = 0.08$ ,  $M = 6.12$ ,  $SD = 1.16$ , and level of new information provided ( $F(2, 64) = 0.228$ ,  $P = 0.797$ ,  $\eta^2 = 0.007$ ,  $M = 5.73$ ,  $SD = 1.57$ ).

### Qualitative Analysis of Questionnaire Responses

Four themes emerged from the textual questionnaire responses: 1) positive perceptions, 2) personal experiences, 3) recommendations, and 4) negative perceptions. Representative responses corresponding to these themes are outlined in Table 6. A majority (69%) of respondents provided positive comments about the video. Several respondents indicated that the information presented in the video was informative and easy to understand and raised awareness of an important issue. Many respondents also commended the creators of the video (e.g.,

"Thank you! This is such an important area"). Other viewers indicated that the video format was effective in delivering evidence-based information (see Table 6).

The second most frequent theme (13%) that emerged from the textual data reflected viewers' personal experiences. That is, several respondents shared personal experiences (e.g., as caregiver, health professional, or researcher) that related to pain in dementia. Respondents indicated that they could relate to the information presented in the video because of the nature of their work, caring for a family member with dementia, or other personal reasons. Several respondents provided suggestions (10%) on how to improve the video (see Table 6). A few respondents commented on ways of improving technical aspects of the video (i.e., incorporating a clickable link to the website for resources, instead of displaying the website URL on the screen), and others expressed the need to expand on the information presented (e.g., include information about nonverbal cues associated with pain). Finally, a small number of respondents (8%)

**Table 6.** Themes and respondent comments based on the short informational video

Theme	Example
Positive Perceptions	<ul style="list-style-type: none"> <li>• “I thought it was an effective way to bring attention to this issue.” (Public)</li> <li>• “I hadn’t thought about this issue at all until I saw the video.” (Public)</li> <li>• “Powerful video to show front line staff in LTC [long-term care] Homes and Physicians.” (Health Professional)</li> </ul>
Personal Experience	<ul style="list-style-type: none"> <li>• “As a person who has Alzheimer’s in the family and a person with chronic pain, I am worried that I will not have adequate pain relief if I am unable to tell someone how and where I hurt” (Caregiver)</li> <li>• “I give workshops for professional and family caregivers on the communication strategies needed to make an emotional connection that leads to safety and cooperation with care—this also provides the tools to locate pain/discomfort.” (Health professional)</li> <li>• “In my case, my husband &amp; I have been caregivers for my mother for over five years.” (Caregiver)</li> </ul>
Recommendations	<ul style="list-style-type: none"> <li>• “Please embed the link into the web page so that I can click on it” (Public)</li> <li>• “I would add information about other non-verbal signs of pain, such as restlessness, moving legs, changes in mood.” (Health Professional)</li> <li>• “Perhaps your next video would show how to make a connection first to assess for pain that would be good to model, you will learn much more about symptoms, read verbal, non-verbal and vocal utterances using good communication practice” (Caregiver)</li> </ul>
Negative Perceptions	<ul style="list-style-type: none"> <li>• “I found the video too short.” (Caregiver)</li> <li>• “The video does not really address the issue adequately because it is so obvious from the grimacing along with his groaning that he is in pain” (Caregiver)</li> <li>• “Too focused on attributing his behaviors to pain, especially the lashing out.” (Public)</li> </ul>

expressed negative views about the video. For instance, a person indicated that the video failed to adequately address the entirety of the problem of pain in dementia and that the video was too short (see [Table 6](#)).

## Discussion

Despite the availability of evidence-based solutions for evaluating and managing pain in dementia, pain continues to be underassessed and undertreated in this population [6–9]. Traditional knowledge mobilization methods (e.g., webinars, workshops) have not been successful in leading to widespread and timely clinical change. To address this concern, we harnessed the power of social media in order to increase the reach of our dissemination campaign. Social media can allow researchers to interact directly with millions of potential knowledge users from around the world. In this investigation, we aimed to reach caregivers, health care professionals, people with dementia, and their families, as well as the public at large. We then evaluated our initiative through Web analytics, content analysis of social media posts in response to our initiative, and a video evaluation questionnaire.

### Increasing Awareness and Discussions About Pain in Dementia Through Social Media

A key objective of our study was to increase awareness of and discussions about the problem of pain in dementia. Our results demonstrated a substantial reach of our social media campaign (with more than 5,000,000 impressions) and of our online repository. Social media analytics indicated that the #SeePainMoreClearly hashtag was used in 31 countries and the website was visited by people in 55 countries. In addition, the Web analytics

demonstrate that the information and messages shared during our campaign had broad international reach. Publication/broadcast of several provincial and national media stories about the #SeePainMoreClearly campaign further increased the reach of our initiative and facilitated the dissemination of information beyond the Twitter platform.

Our findings also showed that the campaign facilitated discussions about pain in dementia. Specifically, results from the comparison of online discussions about pain in dementia indicated that the number of tweets about pain in dementia was significantly greater during the campaign period than it was during the control period. The results of our content analysis of tweets that either used the #SeePainMoreClearly hashtag or were in response to the content disseminated identified specific themes in the conversations about pain in dementia. A majority of the people who engaged with our campaign showed strong support for #SeePainMoreClearly and shared links to our video or online resources. Most people also expressed the need to continue raising awareness of the problem of pain in dementia.

The reach of our initiative can be contextualized in relation to previous health-related social media knowledge mobilization efforts [32,36]. The number of impressions of the top three health-related hashtags for a 4-month period typically ranges from 3 to 21 million [50]. This range suggests that our 5-month campaign (with more than five million impressions) compares favorably with the top three health hashtags. Chambers’ [36] “#ItDoesntHavetoHurt” social media initiative generated more than 130 million content viewers over a 12-month period. An online repository about pediatric emergency care information received approximately 1,200 visitors per month over the course of a year [32].

Discrepancies between previous research and our results may be due to the nature of our initiative (i.e., which, unlike the Chambers initiative, did not have a digital media partner and relied exclusively on advocacy groups and scholarly organizations), differences in the length of evaluation, and the difference in the topics covered (pain in older adults with dementia vs children).

### The Value and Reach of the Short 2-Minute Video

The second aim of the study was to examine the reach and impact of our 2-minute video on stakeholder knowledge through video analytics and the relatively small number of video questionnaire responses. The results were consistent with a strong willingness to share the video with others. A majority of the respondents expressed strong support for use of social media, such as YouTube, as a knowledge mobilization tool. Among all participant groups (e.g., caregivers, health professionals), mean ratings suggested an improved understanding of the problem of pain in dementia as a result of watching the video. There were no significant differences as a function of respondent group in opinions about the use of social media for scientific dissemination, information-seeking behavior, impressions of the video, and level of new information provided. This suggests that our informational video was equally liked by and beneficial for all respondents of our key stakeholder groups.

### Limitations and Directions for Future Research

With the growing use of the Internet as a means of sharing and finding health information, social media and Web-based research dissemination efforts can raise awareness of important health-related topics by tailoring messages and providing pertinent resources to stakeholders. Nonetheless, we recognize that use of social media for research knowledge dissemination represents a new area that does not lend itself to strict scientific control in the evaluation of its effectiveness and reach. We used Web analytics, questionnaires, and content analysis in addition to a comparison of pain in dementia online discussions during the campaign and during a pre-campaign control period.

Several limitations should be considered in interpreting the results of this research. First, a 5-month evaluation period may not be sufficient to demonstrate the full extent to which a social media initiative can raise awareness and increase discussions about a topic. Furthermore, the research articles that served as the basis of the content shared on Web and social media platforms were based on pertinent information that aligned with the two main topics of interest for the initiative (i.e., the underassessment/undermanagement of pain in dementia and available solutions to address this problem). As such, we were not able to cover all possible research domains relating to pain in dementia. Future initiatives could explore broader facets of pain in dementia (e.g., pharmacological

interventions). Moreover, future studies should also examine potential changes in behaviors as a result of longer-term dissemination of the content and messaging. For instance, researchers can explore changes in advocacy efforts (i.e., speaking to a health professional about responsive behaviors) by caregivers and frequency of pain assessment by health professionals before and after exposure to the evidence-based information about pain.

A small investment of a few hundred dollars was made for paid promotions to expand the reach of our video on YouTube. As a result, the number of total views may not be representative of the number of organic views. Our results demonstrate, however, that even with a small monetary investment, researchers can expand the reach and expedite the spread of their messages. That said, from the available analytics, we are not able to determine how many viewers watched the entire 2-minute video. This represents a limitation of the generalizability of our findings.

We recognize that only a very small portion of video viewers responded to our questionnaire. We suspect that this is because most viewers did not see the link, which was not embedded within the video (i.e., the link appeared in the notes below the YouTube video screen). Moreover, a portion of viewers may not have watched the entire video. As such, our results may not be fully representative of the respondent group types and pose limitations to generalizability and replicability. In addition, the Web-based nature and delivery of the study limit its standardization. Perhaps future investigations could explore presenting the video in a lab setting to various stakeholder groups (e.g., caregivers, health care professionals, the public), with the aim of gaining a more representative sample of video viewer impressions.

Video analytics indicated that more men watched the video but more women responded to the questionnaire. There is evidence to suggest gender differences in survey respondent behavior, with women more likely than men to respond to surveys [51]. However, the gender differences in our results are not surprising given that most informal caregivers tend to be women [52,53]. As such, it would be important to sample the views of male caregivers in future research.

Although Web-based platforms present new avenues to scale the dissemination of evidence-based information, it has been shown that social media and the Internet can also be exploited to spread health misinformation [54–56]. The growing use of social media and the proliferation of misinformation could serve as an impetus for researchers and other experts to use these platforms as means of combating false and unscientific information. Nonetheless, sophisticated methods for gauging and ensuring the quality of scientific evidence disseminated online are needed and should be considered in the development of social media-based dissemination efforts. To the best of our knowledge, our investigation represents the first implementation and evaluation of a large-

scale social media initiative on pain in dementia. This effort was largely a grassroots initiative. Future developments could also explore science–media partnerships, consistent with Chambers [36], to reach broader audiences and scale the production of evidence-based content. Moreover, interpretations on the effectiveness of our initiative in stimulating online discussions is limited to the Twitter platform. Given the fast diffusion of content via social media, future investigations should evaluate the level of discussions in other prominent social media platforms, such as Facebook.

## Conclusion

The results from this investigation have implications for closing the knowledge-to-practice gap in dementia care. Findings from the study demonstrate the effectiveness of online knowledge mobilization methods in reaching very broad international audiences quickly. Moreover, our results demonstrate that our knowledge dissemination initiative increased discussions and awareness of the problem of pain undertreatment in dementia. Social media–based knowledge dissemination initiatives can positively impact clinical practice 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 contribute to the growing body of evidence supporting use of Web-based methods for knowledge mobilization.

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## References

1. Bigham BL, Aufderheide TP, Davis DP, et al. Knowledge translation in emergency medical services: A qualitative survey of barriers to guideline implementation. *Resuscitation* 2010;81(7):836–40.
2. Lang ES, Wyer PC, Haynes RB. Knowledge translation: Closing the evidence-to-practice gap. *Ann Emerg Med* 2007;49(3):355–63.
3. Wensing M, Bosch M, Grol R. Developing and selecting interventions for translating knowledge to action. *CMAJ* 2010;182(2):E85–E88.
4. Metzler MJ, Metz GA. Analyzing the barriers and supports of knowledge translation using the PEO model. *Can J Occup Ther* 2010;77(3):151–8.
5. Social Sciences and Humanities Research Council. Guidelines for effective knowledge mobilization. 2019. Available at: [https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge\\_mobilisation-mobilisation\\_des\\_connaissances-eng.aspx](https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge_mobilisation-mobilisation_des_connaissances-eng.aspx) (accessed November 18, 2020).
6. Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *J Pain Symptom Manage* 2000;19(4):240–8.
7. Lautenbacher S. Pain assessment in special patient groups such as those with dementia: At the finishing line or just starting from scratch? *Pain* 2014;155(8):1419–20.
8. Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauser KE. Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *J Pain Symptom Manage* 2008;35(4):388–96.
9. Horgas A, Miller L. Pain assessment in people with dementia. *Am J Nurs* 2008;108(7):62–70.
10. Gibson SJ, Helme RD. Age-related differences in pain perception and report. *Clin Geriatr Med* 2001;17(3):433–56.
11. Herr K, Bursch H, Ersek M, Miller LL, Swafford K. Use of pain-behavioral assessment tools in the nursing home: Expert consensus recommendations for practice. *J Gerontol Nurs* 2010;36(2):18–29.
12. Kaasalainen S, Akhtar-Danesh N, Hadjistavropoulos T, Zwakhalen S, Verreault R. A comparison between behavioral and verbal report pain assessment tools for use with residents in long term care. *Pain Manag Nurs* 2013;14(4):e106–e114.
13. Herr K, Bjoro K, Decker S. Tools for assessment of pain in non-verbal older adults with dementia: A state-of-the-science review. *J Pain Symptom Manage* 2006;31(2):170–92.
14. Hadjistavropoulos T, Herr K, Prkachin KM, et al. Pain assessment in elderly adults with dementia. *Lancet Neurol* 2014;13(12):1216–27.
15. Hadjistavropoulos T, Kaasalainen S, Williams J, Zacharias R. Improving pain assessment practices and outcomes in long-term care facilities: A mixed methods investigation. *Pain Manag Nurs* 2014;15(4):748–59.
16. Fuchs-Lacelle S, Hadjistavropoulos T, Lix L. Pain assessment as intervention: A study of older adults with severe dementia. *Clin J Pain* 2008;24(8):697–707.
17. Herr K, Coyne PJ, Key T, et al. Pain assessment in the nonverbal patient: Position statement with clinical practice recommendations. *Pain Manag Nurs* 2006;7(2):44–52.
18. Hadjistavropoulos T, Herr K, Turk DC, et al. An interdisciplinary expert consensus statement on assessment of pain in older persons. *Clin J Pain* 2007;23(Supplement 1):S1–S43.
19. Royal College of Physicians, British Geriatrics Society and British Pain Society. The Assessment of Pain in Older People: National Guidelines. Concise Guidance to Good Practice Series, No 8. London: RCP; 2007: p. 8.
20. Herr K, Coyne PJ, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: Position statement with clinical practice recommendations. *Pain Manag Nurs* 2011;12(4):230–50.
21. American Medical Directions Association (AMDA). Pain Management in the Long Term Care Setting. Columbia, MD: American Medical Directions Association (AMDA); 2012.
22. Gagnon MM, Hadjistavropoulos T, Hampton AJ, Stinson J. A systematic review of knowledge translation (KT) in pediatric pain. *Clin J Pain* 2016;32(11):972–90.
23. Balas EA, Boren SA. Managing clinical knowledge for health care improvement. *Yearb Med Inform* 2000;09(01):65–70.
24. Morris ZS, Wooding S, Grant J. The answer is 17 years, what is the question: Understanding time lags in translational research. *J R Soc Med* 2011;104(12):510–20.



25. Gough A, Hunter RF, Ajao O, et al. Tweet for behavior change: Using social media for the dissemination of public health messages. *JMIR Public Health Surveill* 2017;3(1):e14.
26. Yaqub U, Chun SA, Atluri V, Vaidya J. Analysis of political discourse on twitter in the context of the 2016 US presidential elections. *Government Inform Q* 2017;34(4):613–26.
27. Dyson MP, Newton AS, Shave K, et al. Social media for the dissemination of Cochrane child health evidence: Evaluation study. *J Med Internet Res* 2017;19(9):e308.
28. Burke-Garcia A, Kreps GL, Wright KB. Perceptions about disseminating health information among Mommy Bloggers: Quantitative study. *JMIR Res Protoc* 2018;7(4):e116.
29. Sibley KM, Khan M, Roche PL, Faucher P, Leggett C. Disseminating the foundations of knowledge translation and patient engagement science through the KnowledgeNudge blog and Twitter profile: Quantitative descriptive evaluation. *J Med Internet Res* 2020;22(6):e15351.
30. Gage-Bouchard EA, LaValley S, Mollica M, Beaupin LK. Cancer communication on social media: Examining how cancer caregivers use Facebook for cancer-related communication. *Cancer Nurs* 2017;40(4):332–8.
31. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: A scoping review. *BMJ Open* 2013;3(5):e002819.
32. Featherstone RM, Leggett C, Knisley L, et al. Creation of an integrated knowledge translation process to improve pediatric emergency care in Canada. *Health Commun* 2018;33(8):980–7.
33. Chambers CT, Dol J, Parker JA, et al. Implementation effectiveness of a parent-directed YouTube video (“It Doesn’t Have to Hurt”) on evidence-based strategies to manage needle pain: Descriptive Survey Study. *JMIR Pediatr Parent* 2020;3(1):e13552.
34. Kelly-Hedrick M, Grunberg PH, Brochu F, Zekowitz P. “It’s totally okay to be sad, but never lose hope”: Content analysis of infertility-related videos on YouTube in relation to viewer preferences. *J Med Internet Res* 2018;20(5):e10199.
35. Riddell RP, O’Neill MC, Campbell L, et al. Featured article: The ABCDs of pain management: A double-blind randomized controlled trial examining the impact of a brief educational video on infants’ and toddlers’ pain scores and parent soothing behavior. *J Pediatr Psychol* 2018;43(3):224–33.
36. Chambers CT. From evidence to influence: Dissemination and implementation of scientific knowledge for improved pain research and management. *Pain* 2018;159(1):S56–S64.
37. Dumbrell D, Steele R. Social media technologies for achieving knowledge management amongst older adult communities. *Proc-Soc Behav Sci* 2014;147:229–36.
38. Chan S, Hadjistavropoulos T, Williams J, Lints-Martindale A. Evidence-based development and initial validation of the pain assessment checklist for seniors with limited ability to communicate-II (PACSLAC-II). *Clin J Pain* 2014;30(9):816–24.
39. Keyhole. Keyhole. 2019. Available at: <https://Keyhole.co/> (accessed September 2, 2019).
40. Del Vecchio P, Mele G, Passiante G, Vrontis D, Fanuli C. Detecting customers knowledge from social media big data: Toward an integrated methodological framework based on netnography and business analytics. *J Knowl Manag* 2020;24(4):799–821.
41. O’Connor S. Using social media to engage nurses in health policy development. *J Nurs Manag* 2017;25(8):632–9.
42. Nolte AC, Nguyen KA, Perelman A, et al. Association between Twitter reception at a national urology conference and future publication status. *Eur Urol Focus* 2021;7(1):214–220.
43. Google LLC. Google Analytics. Available at: <http://www.google.com/analytics/> (accessed September 29, 2019).
44. Nvivo [computer software]. Version 12. Melbourne, Australia: QSR International; 2020.
45. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24(2):105–12.
46. Cavazos-Rehg PA, Krauss MJ, Sowles S, et al. A content analysis of depression-related tweets. *Comput Hum Behav* 2016;54:351–7.
47. Chew C, Eysenbach G. Pandemics in the age of Twitter: Content analysis of Tweets during the 2009 H1N1 outbreak. *PLoS One* 2010;5(11):e14118.
48. Taylor-Powell E. Questionnaire design: Asking questions with a purpose: Cooperative Extension Service. Madison, WI: University of Wisconsin–Extension; 1998.
49. Qualtrics. Qualtrics. Available at: <https://qualtrics.com> (accessed September 1, 2019).
50. Pinho-Costa L, Yakubu K, Hoedebecke K, et al. Healthcare hashtag index development: Identifying global impact in social media. *J Biomed Inform* 2016;63:390–9.
51. Smith G. Does gender influence online survey participation? A record-linkage analysis of university faculty online survey response behavior. ERIC Document Reproduction Service No. ED 501717 2008.
52. Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family-caregivers of people with mental illnesses. *World J Psychiatry* 2016;6(1):7.
53. Akpınar B, Küçükgüçlü Ö, Yener G. Effects of gender on burden among caregivers of Alzheimer’s patients. *J Nurs Scholarsh* 2011;43(3):254.
54. Bailey SJ, LaChapelle DL, LeFort SM, Gordon A, Hadjistavropoulos T. Evaluation of chronic pain-related information available to consumers on the internet. *Pain Med* 2013;14(6):855–64.
55. Chou WS, Oh A, Klein WM. Addressing health-related misinformation on social media. *JAMA* 2018;320(23):2417–8.
56. Wang Y, McKee M, Torbica A, Stuckler D. Systematic literature review on the spread of health-related misinformation on social media. *Soc Sci Med* 2019;240:112552.