RESEARCH PAPER

Public Health Messaging during the COVID-19 Pandemic and Its Impact on Family Caregivers' COVID-19 Knowledge

Messages de santé publique pendant la pandémie de COVID-19 et leur impact sur les connaissances des proches aidants en matière de COVID-19

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Abstract

Background: Enabling accurate, accessible public health messaging is a critical role of public health officials during a pandemic, but family caregivers of people living with dementia (PLWD) have rarely been specifically addressed in public health messaging.
Objective: The objective of this study was to examine how family caregivers for people living with dementia access and evaluate public health messaging in Alberta.
Method: An online survey was conducted with family caregivers for PLWD (n = 217).
Results: Most respondents rated public health messaging as good or excellent (63.9%), but specific information about how to access caregiving information (69.5%) and what to expect in the future (49.1%) was rated as less than good. Family caregivers also identified how to care for a PLWD during the pandemic (57.5%) as a key information need. Healthcare providers/workers were the least frequently used source of public health messaging. Almost all family caregivers (94.4%) rated their own COVID-19 knowledge as good or excellent.
Discussion: Tailored, context-driven public health messaging for family caregivers of PLWD is critically needed.

Résumé

Contexte : Communiquer des messages de santé publique précis et accessibles est un rôle essentiel des responsables de la santé publique pendant une pandémie, mais les proches aidants des personnes atteintes de démence en sont rarement les destinataires spécifiques.
Objectif : L'objectif de cette étude est d'examiner comment les proches aidants des personnes atteintes de démence prennent connaissances et évaluent les messages de santé publique en Alberta.
Méthode : Un sondage en ligne a été mené auprès de proches aidants de personnes atteintes de démence (n = 217).
Résultats : La plupart des répondants qualifient les messages de santé publique de bons ou d'excellents (63,9 %), mais ils qualifient de moins bon les renseignements précis sur la façon d'obtenir des informations concernant les soins (69,5 %), ou encore les messages concernant les perspectives d'avenir (49,1 %). Les proches aidants ont également indiqué que la façon de prendre soin d'une personne atteinte de démence pendant la pandémie (57,5 %) était une information nécessaire. Les fournisseurs de soins et les travailleurs de la santé constituent les sources d'information sur la santé publique les moins fréquemment utilisées. Presque tous les proches aidants (94,4 %) ont évalué leurs propres connaissances sur la COVID-19 comme étant bonnes ou excellentes.
Discussion : Il est nécessaire de formuler des messages de santé publique adaptés et axés sur le contexte des proches aidants des personnes atteintes de démence.

Introduction

The COVID-19 pandemic, now well into its third year, remains a global focus and continues to challenge governments across multiple jurisdictions to manage public safety and minimize disease transmission through a myriad of ever-changing public health measures (Government of Canada 2022a). Since the first reported case in Canada in January 2020, 12% of all Canadian media headlines have been related to the COVID-19 pandemic (ProQuest n.d.). The sheer volume of information has proven to be overwhelming, as has the amount of misinformation (Bridgman et al. 2020; Caulfield 2020). Misinformation about the COVID-19 virus is especially problematic as false cures, incorrect transmission and risk information and confusion around usage of masks and personal protective equipment can deter protective health behaviours (van der Linden et al. 2020). The proliferation of misinformation may prevent effective virus containment and may reduce widespread public adoption of critical health measures (Harvey 2021). To that, government agencies have responded accordingly with 18.7% of the Public Health Agency of Canada's (PHAC's) current online literature (2015–present) being related to COVID-19. In comparison, only 6.72% of PHAC's current online content is related to influenza, and 1.73% is related to the recent Zika virus outbreak (Government of Canada n.d.).

The availability of accurate, accessible and comprehendible public health information is a primary responsibility of public health officials (WHO 2005). During a health crisis or natural disaster, effective public health messaging can ease a nervous public, deliver much needed information, encourage societal cooperation and ultimately save lives (WHO 2005). In Canada, public health is overseen at federal, provincial and regional levels. Provinces, however, retain healthcare jurisdiction, resulting in each province implementing its own COVID-19 response strategy, including public health recommendations, policies and messaging (Detsky and Bogoch 2020). The Province of Alberta, similar to many Canadian provinces, has engaged in a multi-phased media strategy to support key COVID-19 public health measures and provincial pandemic responses, including (1) COVID-19 information, (2) economic relaunch strategy, (3) provincial recovery plan and (4) protecting at-risk Albertans (Government of Alberta 2022). The last phase has been directed at strategies and information for vulnerable older adults with underlying medical conditions, including those living with dementia.

Older adults are most at risk of mortality from COVID-19 infection. In Canada, older adults over the age of 60 account for only 36% of COVID-19 cases, but 95% of the country's COVID-19–related deaths, with 82% of those deaths occurring in supportive living facilities (PHAC 2020). Alberta rates are similar, with the average age of a COVID-19 hospitalization being 60, approximately 90% of COVID-19 cases occurring in adults over the age of 70 and approximately 90% of deceased Albertans having two or more underlying medical conditions (Government of Canada 2022b). One of the common chronic health conditions is dementia, with over 564,000 older Canadians living with dementia (Chambers et al. 2016). In Alberta, there are over 50,000 people living with dementia (PLWD), which exceeds 1% of the province's population (Alberta Health Services 2016). The progressive cognitive decline that defines dementia means that PLWD become increasingly reliant on family caregivers as their disease progresses. Family caregivers of PLWD have been shown to report higher associated burden and spend more time caring than other, non-dementia caregivers (Brodaty and

Donkin 2009). Caregiving burden is not surprising as family caregivers provide an average of 26 hours of care per week for their family member with dementia, and 45% of these caregivers experience significant distress (CIHI 2016b). The COVID-19 public health measures have further complicated their challenging caregiving roles by reducing available services and supports (Hoffman et al. 2020).

Historically, family caregivers have been largely unacknowledged in times of crises despite being valuable "first responders" who protect the vulnerable populations for whom they provide care (Elkins et al. 2014). The COVID-19 pandemic has been no exception. Recognizing this gap, Dang et al. (2020) drafted policy recommendations for US health systems on how to communicate with and support caregivers during the COVID-19 pandemic. In contrast, the provincial government of Alberta has directed resource- and communication-assistance documents to operators of care facilities for older adults and support agencies, rather than to the family caregivers themselves (Government of Alberta 2020a, 2020b). Given that Alberta family caregivers face service and support challenges similar to those of their American counterparts (Dang et al. 2020), it is important to examine the clarity and usefulness of the current public health messaging system, as well as the health information needs of family caregivers of PLWD during the COVID-19 pandemic. Doing so will support family caregivers in providing critically needed care for their family members with dementia while maintaining their own health.

As such, the purpose of this study is to examine how family caregivers of PLWD evaluate public health messaging in Alberta. In this study, we use the term *public health messaging* to delineate health messages and health restrictions about the COVID-19 pandemic that have been generated by or are being disseminated by a provincial government, typically shared with the public by either designated provincial leaders (e.g., the health minister, the premier) or the provincial health officer/chief medical officer. The objectives of the study are to examine (1) where family caregivers are getting COVID-19–related public health information and (2) if the information is meeting their needs. The goal is to aid public health officials at the regional, provincial and federal levels in (a) providing clear and applicable information through the ongoing COVID-19 pandemic about the changing disease itself and dynamic public health measures and (b) understanding the clarity and usefulness of public health messaging in future public health emergencies.

Method

In partnership with our community partners, the Alzheimer Society of Calgary and the Dementia Network Calgary, a community advisory committee (CAC) including participatory members from our study (family caregivers) was convened to guide this study. The CAC provided the research team with input and direction through the survey design, implementation of the survey and the interpretation of the final results. Research ethics approval for this study was attained from the University of Calgary Research Ethics Board (REB20-0855).

Participants

The study population included those living in large and small population centres in Alberta (Statistics Canada 2017) and are family caregivers of PLWD across the care continuum: at home in the community, in assisted/supportive living and in long-term care. Informed consent was obtained from all study participants. Participant eligibility included family caregivers over the age of 18 providing care for a PLWD. Study participants were recruited through the family caregivers' networks of our community partners.

Data collection

Using the SurveyMonkey platform, an online survey was conducted in late spring of 2020, just after the peak of the first wave in Alberta. A link to the survey was distributed to family caregivers for PLWD through our community partners using electronic newsletters, organization web pages and social media pages. The study discussed here is a part of a parent study, which also included focus groups to further explore the experiences of family caregivers.

Measures

Survey questions were adapted from published scales that collect data regarding public risk perception, behaviour, knowledge and trust, as well as caregiver burden. The scales were adapted specifically for this study with the guidance of our CAC. We also included two single-item questions in this survey to assess respondents' rating of personal wellness (health and quality of life). The scales are as follows:

PUBLIC HEALTH MESSAGING

This scale was adapted from the Lewy Body Dementia: Caregiver Burden and Unmet Needs (Galvin et al. 2010) questionnaire, which asks about needs of family caregivers for PLWD. Measured on a five-point Likert scale (1 = *very poor*, 5 = *excellent*), higher scores indicate greater approval rating of public health messaging, while lower scores indicate lower approval. Coefficient α for this six-item scale in this study is 0.87.

SELF-RATED COVID-19 KNOWLEDGE

This scale was adapted from the WHO Regional Office for Europe's (2020) COVID-19 Snapshot Monitoring (COSMO Standard) questionnaire, which asks about COVID-19 knowledge and information confidence. It is measured on a five-point Likert scale (1 = *very poor*, 5 = *excellent*). Higher scores indicate greater knowledge levels about COVID-19, while lower scores indicate lower knowledge levels. Coefficient α for this four-item scale in this study is 0.90.

PUBLIC HEALTH INFORMATION SOURCES

This scale was adapted from the WHO Regional Office for Europe's (2020) COSMO Standard questionnaire, which asks about COVID-19 knowledge across nine common information sources. It is measured on a five-point Likert scale (1 = *never,* 5 = *multiple times per day*). Higher scores indicate higher use of media sources for information, while lower scores indicate less frequent use of media sources for information.

COVID-19 INFORMATION NEEDS

This scale was adapted from the Behavioural Insights for COVID-19 scale (Betsch et al. 2020). The seven questions ask what specific knowledge about COVID-19 is needed. Responses are yes or no.

SELF-RATED HEALTH

A single item question was used to assess self-rated health, measured on a five-point Likert scale (1 = *poor,* 5 = *excellent*). Higher scores indicate better self-rated health, while lower scores indicate poorer self-rated heath.

SELF-RATED QUALITY OF LIFE CHANGE

A single item question was used to assess self-rated quality of life change during the pandemic, measured on a three-point Likert scale (1 = *less than usual,* 3 = *more than usual*). Higher scores indicate better self-rated quality of life, while lower scores indicate poorer self-rated heath during the pandemic.

CONTROL VARIABLES

Seven control variables were included in the data analyses: five individual family caregiver variables and two variables about the PLWD the participant cares for. The individual family caregiver variables include (a) gender, (b) age, (c) relationship to PLWD, (d) highest level of education and (e) length of time as a caregiver (in years). The variables about the PLWD include (a) gender and (b) age.

Data analysis

Survey data were analyzed quantitatively with IBM Statistical Package for Social Sciences Software (IBM SPSS) version 26 using descriptive and correlation statistics (Field 2017).

Results

A total of 217 surveys were completed and used for analysis. A survey was considered complete if at least 75% of the questions were answered. The majority of the respondents (Table 1) were female caregivers (77.8%), had a university degree (56.5%) and were either 51–60 years of age (28.7%) or 61–70 years of age (28.7%). The majority of the PLWD they cared for were women (61.1%), 81 years of age or older (54.6%) and either a spouse/partner (46.1%) or a parent (40.6%). Zero-order correlations, sample means, standard deviations, as well as internal consistency alphas for the study variables, are provided in Table 2. An analysis of the descriptive table identified no multi-collinearity issues (Field 2017).

TABLE 1. Sample demographics

	N	Percentage
Gender		
Female	168	77.4
Male	47	21.7
Age		
≤ 50 years	26	12.0
51–60 years	62	28.7
61–70 years	62	28.7
71–80 years	49	22.7
> 80 years	17	7.9
Relationship to PLWD		
Spouse/partner	100	46.1
Child/child-in-law	88	40.6
Other relative	26	12.0
Neighbour/friend	3	1.4
Education		
High school diploma/equivalent or less	32	14.8
Community/technical college	62	28.7
University degree	90	41.7
Graduate degree	32	14.8
Length of time as a caregiver		
< 1 year	15	6.9
1–2 years	30	13.8
2–4 years	63	29.0
> 4 years	109	50.2
PLWD's gender		
Female	132	61.1
Male	84	38.9
PLWD's age		
≤ 50 years	0	0
51–60 years	3	1.4
61–70 years	27	12.5
71–80 years	68	31.5
> 80 years	118	54.6

N = 217. Columns may not total exactly due to rounding and/or missing information.
PLWD = people living with dementia.

TABLE 2. Descriptive statistics, correlations and scale reliabilities

Variable	M	SD	α	1	2	3	4
Alberta public health messaging	3.66	0.70	0.87		0.51**	0.27**	0.16*
Self-rated COVID-19 knowledge	4.31	0.57	0.90	0.51**		0.13	0.08
Self-rated health	3.14	0.99	n/a	0.23**	0.13		0.06
Quality of life	1.49	0.58	n/a	0.16*	0.08	0.06	

*$p < 0.05$. **$p < 0.01$ (two-tailed test).

Regarding public health information sources, the majority of the respondents reported using the television (79%), family/friends (68.1%) and websites (63.4%) for information. Information sources *not used* by the sample respondents included social media (70.4%), newspapers (63%), colleagues (61.6%), radio (57.3%) and search engines (55.9%). Healthcare providers/workers were *the least frequently used source* of public health information (79.2% do not use). Sources for public health information are shown in Table 3.

TABLE 3. Public health information sources

	Used (Number/percentage)			
Source	Never	Occasionally	Weekly	Daily
Television	19/8.9%	26/12.1%	13/6.1%	**156/72.9%**
Newspaper	**95/45%**	38/18%	8/3.8%	70/33.2%
Family/friend	4/1.9%	63/30%	69/32.9%	**74/ 35.2%**
Colleague	**70/33.2%**	60/28.4%	52/24.6%	29/13.8%
Healthcare provider/ worker	56/26.4%	**112/52.8%**	31/14.6%	13/6.1%
Websites	21/9.9%	57/26.8%	32/15%	**103/48.3%**
Social media	**94/44.1%**	56/26.3%	15/7%	48/22.6%
Search engines	46/21.6%	**73/34.3%**	42/19.7%	52/ 24.5%
Radio	**74/35.1%**	47/22.3%	21/10%	69/32.7%

N = 217. Rows may not total exactly due to rounding and/or missing information. Bolded items represent the most frequently chosen response by media sources.

Regarding needed COVID-19 information (Table 4), the majority of respondents identified scientific progress in both vaccine development (61.8%) and COVID-19 treatment (57.6%) and in how to care for a PLWD during the pandemic (57.5%) as the most needed information. In addition, the majority of respondents identified the following information as not being needed: personal coping stories (68.2%), COVID-19 symptoms (63.1%), travel restrictions (62.7%) and COVID-19 transmission prevention (57.6%).

Overall, public health messaging was rated good or excellent by the majority (63.9%) of respondents. Public health messaging around COVID-19 infection, including the spread and symptoms, were rated good or excellent by 87.9% and 84.1% of family caregivers, respectively. Almost half of family caregivers (49.1%) rated public health messaging around what to expect about COVID-19 in the future as less than good. Although the majority (76.9%)

TABLE 4. Information needs

Information needs	Number/percentage	
	No	**Yes**
COVID-19 symptoms	137/63.1%	80/36.9%
Personal coping stories	148/68.2%	69/31.8%
Scientific progress in vaccine development	83/38.2%	**134/61.8%**
Scientific progress in COVID-19 treatment	92/42.4%	**125/57.6%**
COVID-19 transmission prevention	125/57.6%	92/42.4%
How to take care of PLWD	92/42.4	**125/57.6%**
Travel restrictions	136/62.7%	81/37.3%

N = 217. Rows may not total exactly due to rounding and/or missing information.
PLWD = people living with dementia.
Bolded items represent information needs identified by the majority of respondents.

of family caregivers rated public health messaging on where to find COVID-19–related information as good or excellent, 69.5% of family caregivers rated messaging around where to find caregiving-related information as less than good. Caregiving-related information in this instance reflects information about how to provide care for a PLWD in the event of a COVID-19 diagnosis.

Regarding family caregivers' self-rating of their knowledge about COVID-19 (including knowledge about the virus, how it spreads and how to protect themselves and the PLWD they care for from infection), almost all family caregivers (94.4%) rated their own knowledge as good or excellent. The majority of family caregivers also rated their own health as good (40.3%) or very good/excellent (37.1%). Conversely, the majority of family caregivers rated their quality of life during the pandemic as lower than usual (55.3%).

Discussion

Our study found that the majority of family caregivers for PLWD rated their knowledge about COVID-19 as good/excellent overall, but public health messaging could be improved in specific areas to better support their needs during the ongoing COVID-19 pandemic. Public health officials should pay additional attention to (1) providing information on scientific progress of vaccine development, (2) treatment options for COVID-19 and (3) the provision of care for a PLWD during the pandemic. These findings align with other studies that have investigated the experiences of family caregivers in Canada and found that role recognition of family caregivers, improved communication needs, more timely communication and navigation support to access needed resources are lacking (Parmar et al. 2021; Weeks et al. 2021). Furthermore, the findings suggest that tailored public health messaging is needed in both a short-term context (such as COVID-19 transmission strategies) and in a long-term context (such as caring for PLWD who contract COVID-19) and future public health emergencies, which aligns well with public health emergency communication models (Seeger et al. 2018) that emphasize the importance of transparency, clarity and focus in public health messaging.

Family caregivers' rating of public health messaging on information about COVID-19 and their rating of self-knowledge about COVID-19 was found to have a significant relationship. A higher rating of public health messaging equating to a higher self-knowledge rating offers insights into effective strategies for health messaging dissemination. Public health messaging provides healthcare policy makers and decision makers with a critical avenue to disseminate accurate and scientific knowledge while also building the public's confidence in their own knowledge about managing a novel virus. Effective communication to the public regarding emergency health threats is an ongoing requirement (Wray et al. 2008), both during successive COVID-19 infection surges and in future public health emergencies. While individual characteristics are often a factor in health literacy and how public messaging is interpreted (Freedman et al. 2009), it is important to note that the overarching finding of public health messaging being related to higher self-knowledge was not a factor of individual attributes. Neither self-rated health nor quality of life were significant with COVID-19 self-knowledge ratings. Moreover, gender, education and length of time spent caregiving were also non-significant. As such, this suggests that consistent and tailored public health messaging may be able to mitigate barriers to public health communication/knowledge acquisition, such as level of education (Ghio et al. 2020) and language barriers (Lin et al. 2014).

For family caregivers, tailored public health messaging, with information that addresses personalized needs and is context driven, is critically required (Daellenbach et al. 2018). Specifically, a key information need of our respondents was how to continue to provide care for a PLWD during the pandemic. Many public health guidelines – such as mandatory masking, handwashing, social distancing and the restrictions placed on accessing supportive living and long-term care facilities – disproportionately impacted PLWD and, therefore, changed the nature of providing care for family caregivers (CIHI 2016a, 2020; Wang et al. 2020). For PLWD, cognitive impairment makes it difficult to follow public health guidelines and places another layer of complexity and burden on family caregivers when providing care. For family caregivers in the community, many of the services available pre-pandemic – such as home care and adult day programs – were either stopped or severely limited, likewise contributing to family caregivers' burden (Alberta Health Services 2020; Hoffman et al. 2020). Targeted information about ongoing changes to public health measures, how to address the changes and what to expect in the future for when/how services will be reinstituted would assist family caregivers of PLWD in their care provision role.

Typically, family caregivers over the age of 60 have been found to infrequently utilize online sources, such as web pages and search engines, to obtain information in comparison with their younger counterparts (Hesse et al. 2005). While the majority of our respondents reported accessing websites for COVID-19 information daily, that same majority reported never accessing social media platforms. As such, provincial governments should remain aware that social media should be considered as one but not the only venue for successfully disseminating public health messaging, with the source being tailored to the preferences of the individual (Toppenberg-Pejcic et al. 2019).

One of the surprising findings from our study was that the majority of our respondents had not engaged with a healthcare provider to gain information about COVID-19. This is contrary to typical healthcare concerns, in which most individuals rate their healthcare provider as a key source of information. However, it does mirror Canadian data that show a significant decline in physician services during the opening months of the pandemic (Statistics Canada 2021). While family physicians were able to shift to *virtual visits* during the pandemic, it may be that the respondents in our survey did not have the need for physician consult or were not comfortable using a virtual service and thus chose to not seek healthcare provider consultation. Therefore, providing caregiving information through venues that are frequently used by older adults, such as television, might greatly increase the likelihood that key public health information is received by its intended audience. As such, it is evident that governments and healthcare systems should consider the sources perceived as trustworthy and consistent to convey key information to family caregivers (Rebmann et al. 2008).

Based on these findings, our key recommendations to public health and government authorities are as follows:

- *Utilize diverse media sources* to communicate messaging, including television, radio and print media, in addition to online sources.
- *Tailor information* to the needs of specific vulnerable populations, such as family caregivers for PLWD, including information and advice on topics such as explaining public health measures to people with dementia and cognitive impairment, accessing respite if the caregiver contracts COVID-19 and accessing long-term care, as well as how and when community resources are being adapted/reinstated.
- *Focus on building capacity* in healthcare providers of family caregivers for PLWD with regard to care communication methods during public health emergencies. Provide education, training and support tools to aid healthcare providers in both offering alternative care services (e.g., virtual care) and helping transition their clients/patients/families to using alternative care services.

With the aggressive dynamism of the COVID-19 virus, the ongoing pandemic will likely continue to be a public health emergency for the near future. As such, it is inevitable that public health restrictions and related messages by provincial governments will continue to be in the forefront of government communications to protect public safety, maintain the efficacy of provincial health systems, combat vaccine hesitancy and safeguard the vulnerable from this disease. Future research examining the effect of public health messaging and measures is needed to understand how family caregivers of older adults access and use public health information and how the pandemic continues to challenge their critical role as caregivers.

Study limitations

As this study examined family caregivers for PLWD in only one province and used a small sample, the results are not necessarily generalizable to other family caregivers across other provinces and at all government levels, all of which have faced unique challenges related to the COVID-19 pandemic and the resulting public health messaging. However, the results do offer overarching insight into where family caregivers access public health messaging and what they see as communication gaps. As such, many government entities can garner insight into optimizing the use of media channels and public health messaging content. In addition, the study only examined family caregivers for PLWD, so the findings are not representative of family caregivers for individuals with other chronic diseases. Yet it is known that family caregivers for frail older adults experience many of the same challenges that their family caregiver peers do while caring for PLWD (Sinha 2012; Walston et al. 2006). Thus, the findings of this study offer guidance in communicating with family caregivers caring for individuals across the care/disease spectrum. A final limitation in this study reflects the time passage since the data were collected in the first wave of the COVID-19 pandemic. Moreover, the findings reflect the most restrictive phase of public health measures and may not reflect family caregivers' viewpoints through the successive waves and loosening of public health measures. However, COVID-19 continues to be a dominant force in our society due to virus mutations and infection surges, as well as the vaccine hesitancy evident in many provinces. It is, therefore, ever more important for governments to pursue effective public health messaging, for which this study's findings offer guidance.

Conclusion

A key component of PHAC's mission statement is *providing information to support informed decision making*. This is challenging amid an unprecedented global health crisis and constant mutations of the COVID-19 virus because the information and public health policies must likewise continuously evolve. Although Canadian and provincial public health agencies have made great strides in providing COVID-19 information, vulnerable populations, such as PLWD and their caregivers, have not been specifically targeted. The findings from this study highlight the importance of tailored messaging and information sources, which can assist public health messaging to better support the needs of family caregivers and the PLWD for whom they provide care.

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