ORIGINAL RESEARCH

Ensuring Clinical Practice Guidelines Meet the Needs of the End-User: a Prioritization Survey for Guideline Topics for Behavioural and Psychological Symptoms of Dementia

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ABSTRACT

Background

Behavioural and psychological symptoms of dementia (BPSD) are complex to assess and manage, and a lack of updated clinical practice guidelines (CPGs) leads to variation in clinical practice. When generating CPGs, involvement of end-users in developing and prioritizing topics is key to creating effective recommendations.

Methods

To inform the creation of a CPG for the management of BPSD, we completed a Canada-wide online BPSD topic prioritization survey using Qualtrics. In January-March 2023 the survey was disseminated widely to identify preferred terminology to use in the guideline and to prioritize topics to be included.

Results

Two hundred fifty-four persons responded to the survey. Participants were mostly female (88.2%), identified as women (87.0%), were aged 50-64 (37.0%), from Ontario (69.7%), and from nursing roles (n=83). BPSD was the most preferred terminology (32.1%) followed by responsive behaviours (26.2%). Seven topics were reviewed for guideline inclusion, with priority placed on prevention, non-drug management, and prodromal symptoms. Comments from participants identified concerns around validity of detection tools, possible lack of available evidence, and conflict between standardized approaches versus the need for individualized care.

Conclusions

Involvement of end-users in the determination of terminology and prioritization of topics was an effectual way to ensure CPGs represent the needs of the user.

Key words: behavioural and psychological symptoms of dementia, clinical practice guidelines, survey

INTRODUCTION

An estimated 733,040 Canadians live with dementia, a number projected to increase as the Canadian population ages.(1,2) There are numerous types of dementia, the most common of which are Alzheimer's disease and vascular dementia.(3) Curative treatments for dementia do not exist; however, there are strategies to manage symptoms and medications which can help with temporary symptomatic improvements.(4)

Behavioural and psychological symptoms of dementia (BPSD) affect almost all persons living with dementia at some point during their illness, and can include numerous symptoms like agitation or aggression.(4,5) BPSD are associated with negative outcomes like mortality, morbidity, hospitalizations, increased health-care costs, and the need for higher levels of care.(6-8)

BPSD often contribute to the stigma associated with dementia.(9,10) BPSD can be viewed as a communication of unmet needs which requires a person-centred approach to care that aims to address the root cause of the behaviour. Failure to take a person-centred approach to managing BPSD may result in unmet needs being overlooked, reduced quality of life for the person living with dementia, challenges for health-care providers, and inappropriate treatment with off-label medications.(9,10)

Given how common BPSD are, and the negative consequences associated with their occurrence, it is critical to have clinical practice guidelines (CPGs) that address the assessment and management of these symptoms and reflect current evidence-based care practices. A recently conducted systematic review identified that existing guidelines addressing care for BPSD provide inconsistent recommendations for practice, and lack consideration of applicability.(11) In response to the lack of clear guidance directing care for BPSD in dementia, the Canadian Coalition for Seniors' Mental Health (CCSMH) developed the first Canadian CPG for BPSD in dementia in 2024.(12) Prior to guideline development, end-users were engaged to identify important topics for inclusion in the CPG. It is essential to engage end-users in the CPG development process to ensure the relevance of recommendations to end-users and the successful uptake or adoption of the CPG.(13,14) The present study describes the end-user engagement undertaken as part of the CPG development process.

The purpose of the study was to identify the priority topics, as identified by end-user groups, for the 2024 CCSMH CPG on the assessment and management of BPSD.(12)

METHODS

A single online survey was conducted to reach end-user groups across Canada and gather data on end-user-identified priority topics. The goal of the survey was to identify feasible topics to prioritize for the current guideline, and to identify next steps or topics to explore in future guidelines. The survey was approved by the University of Calgary's Conjoint Health Research Ethics Board (REB22-1716).

Participants

Survey participants were CPG end-users who self-identified as living with dementia, caregivers of persons living with dementia (including paid, family, or friend caregivers), clinicians who provide care to persons living with dementia, and policymakers working in dementia care. Participants had to be Canadian citizens or permanent residents of Canada to focus on the Canadian context, and have access to email and the internet.

Participant Recruitment

All participant recruitment occurred virtually through the study investigators' networks and known intermediary groups working with the research team at the time of development (i.e., CCSMH, Canadian Academy of Geriatric Psychiatry, Behavioural Supports Ontario, Provincial Geriatrics Leadership Ontario, Canadian Gerontological Nursing Association). Investigators and organizations supporting the recruitment process sent out invitations to participate in the survey via email to their networks. Eligible participants who received the email to participate followed the link to the online survey to read more about the study, consented to participate in the survey, and completed the survey. Snowball sampling was used to allow persons who received the email invitation to participate to forward the invitation to their contacts.

Survey Procedure

The one-time online survey was conducted via the online survey platform Qualtrics (Qualtrics. Provo, Utah; https://www.qualtrics.com) (see Appendix S1 in the supplemental materials). The survey took participants about ten minutes to complete. The survey collected demographic information including age, role/profession, sex, gender, and province/territory of residence. Participants were able to select if they were interested in being contacted by the research team in the future for further studies related to care for behaviours in dementia. Participants could complete the survey using either the English language or French language versions. The survey was completed by participants between January 26, 2023 and March 21, 2023.

Survey Content

Survey participants were asked about their preferred terminology for referring to behavioural changes in the context of dementia, if topics identified by the research team should be included in the new guideline, and to identify any new topics of importance not noted by the research team. Preferred terminology options were identified from literature included in the previously completed systematic review and by the panel of experts established for the guideline creation.(11,12) The research team consisted of geriatricians and geriatric psychiatrists with expertise in dementia care.

To have clearly understood, widely accepted, and person-centred terminology used in the guideline, participants were asked to indicate which term of those presented was their preferred terminology to refer to the general topic of behaviour in the context of dementia. Participants could select "other" and identify a term not listed. The terms identified by the research team and presented to participants included behavioural and psychological symptoms of dementia; behavioural changes in dementia; behaviours in dementia; behaviours of dementia; changes in mood, personality, or behaviour in dementia; neuropsychiatric symptoms of dementia; personal expressions; responsive behaviours; or comportements réactifs (French language version only).

For the survey section on guideline topics identified by the research team, participants were provided with a link to the existing CCSMH 2006 Guideline on Mental Health Disorders in Long-Term Care(15) to view as desired. In addition to the guideline topics presented in the 2006 guideline, the research team proposed seven general topics for inclusion in the development of the current guideline. Participants only voted on new topics. The topics related to behaviours in dementia were collaboratively brainstormed by the research team. Participants were asked if they thought the topic should be included or excluded in the current guideline, and were able to comment on their choice in a free text box following each suggested topic. Suggested topic areas were kept broad to ensure a wide range of areas and applicability were captured. Participants also had the opportunity to list up to five additional priority topics to be considered for inclusion in the current guideline using free text boxes within the survey.

Data Analysis

Participant responses were included in the analysis if consent was indicated and the survey was initiated, regardless of how complete the survey was. Participant demographic information was totalled by the responses within each category and expressed as a percentage. Preferred terminology was presented as a percentage of total respondents, as well as the preferred terminology by participant role. Responses to guideline topics identified by the research team were reported as percentages of the total number of respondents for each topic. Participant comments related to research team-identified topics were thematically grouped and presented by topic. Overarching themes spanning across topics were identified. All new topics suggested by participants were thematically grouped by one researcher and independently verified by a second researcher.

The highest-ranking proportion was selected for which terminology should be used in the guideline. Similarly, we took the five highest ranking proportions answered "Include in Current Guideline" across all seven team-identified topics to be included in the guideline.

RESULTS

A total of 254 participants completed the survey. Participant demographic information is presented in Table 1. The typical participant identified as a woman, was in a nursing health-care provider role, resided in Ontario, and was between the ages of 35 to 64. Due to sampling strategies, we were unable to determine the response rate.

TABLE 1 (part 1 of 2).
Participant demographic information from 254 respondents

TABLE 1 (part 2 of 2).
Participant demographic information from 254 respondents

Component	*Response n (%)*
Role[a]	
Nurse (RN, LPN)	83
Friend or family caregiver	38
Psychiatrist or geriatric psychiatrist	37
Allied health[b]	31
Manager	31
Behavioural Supports Ontario (BSO) or behaviour support worker[c]	28
Other[d]	22
Educator	11
HCA or PSW	9
Family physician	9
Policymaker	7
Geriatrician	6
Nurse practitioner	5
Person living with dementia	3
Age Group	
18-34	44 (17.32%)
35-49	89 (35.04%)
50-64	94 (37.01%)
65-74	20 (7.87%)
75-84	5 (1.97%)
85+	2 (0.79%)
Sex	
Female	224 (88.19%)
Male	30 (11.81%)
Gender	
Woman	221 (87.01%)
Man	30 (11.81%)
Other	3 (1.18%)
Province of Residence	
Ontario	177 (69.69%)
Manitoba	20 (7.87%)
British Columbia	18 (7.09%)
Alberta	19 (7.48%)
Quebec	6 (2.36%)
New Brunswick	4 (1.57%)
Saskatchewan	4 (1.57%)
Nova Scotia	2 (0.79%)
Newfoundland and Labrador	3 (1.18%)
Prince Edward Island	1 (0.39%)

[a] n=11 participants identified three roles and n=44 participants identified two roles.

[b] Allied health includes the following roles: social work, occupational therapy, recreation therapy, physical therapy, addictions, pharmacy, psychologist, psychotherapist, mental health clinician.

[c] BSO and behaviour support worker include the following reported roles: Clinical Behaviour Response Specialist - BSO, Behaviour Support Interventionist - BSO, BSO Assistant, BSO long-term care (LTC) Lead, BSO Program Lead in LTC homes, Behavioural Support Ontario, BSO Community Outreach Worker, BSO - Therapeutic Recreation, Behaviour Supports Ontario Clinical Leader, Behavioural Supports Ontario Community Outreach Worker, Behavioural Consultant – BSO, BSO Counsellor, Coordinator of BSO and Transition Services, BSO Behavioural Outreach Worker, Behavioural Outreach Worker, Project Specialist BSO Provincial Coordinating Office, Behavioural Support Lead, Behavioural Support Worker, Clinical Behaviour Response Specialist, Behavioural Support Facilitator with Alzheimer's Society, Behaviour analyst.

[d] Other category includes: Alzheimer's Society staff, Advanced practice nurse, Care navigator, Care of the Elderly physician, Graduate student, Knowledge transfer and exchange associate, Neurologist, Older adult, Project manager, Psychogeriatric resource consultant, Team leads, Transition activation support lead, Volunteer, Researcher, Hospital director.

Preferred Terminology

Amongst all participants, behavioural and psychological symptoms of dementia (32.14%, n=81/252) was the preferred terminology for referring to the general topic of behaviours in the context of dementia (see Appendix S2 in the supplemental materials).

When evaluated by participant role, BPSD was the highest proportion choice for persons living with dementia

(66.67%), nurses (registered nurse [RN], licensed practical nurse [LPN]) (37.04%), psychiatrists (48.65%), nurse practitioners (60.00%), and family physicians (55.56%). BPSD was tied with neuropsychiatric symptoms of dementia amongst geriatricians (50.00% each) and with responsive behaviours amongst allied health participants (25.81% each). Responsive behaviours was the most common selection for friend or family caregivers (28.95%), health-care aides (HCAs) or personal service workers (PSWs) (44.44%), educators (54.55%), managers (32.26%), and specialized behavioural providers (35.71%). Policymakers indicated equal agreement between responsive behaviours and personal expressions (28.57% each).

Research Team-Identified Topics

The seven research team-identified topics with the number of respondents indicating they should be either included or excluded in the current guideline are reported in Table 2. The topics ranged from 225 to 228 responses per topic from a total of 254 participants. For each topic, some participants chose only to provide a comment and did not indicate if the topic should be included or excluded. At least 90% of participants chose to include topics on prevention (96%), on prodromal symptoms (91%), on interventions (97%), and on training (90%) in the current guideline. Topics on screening (11%), on models of care (14%), and on virtual care (15%) had the greatest degree of participants selecting that the topic be excluded from the current guideline.

Overarching themes from participant comments on the seven topics were identified (Table 3). Overall, participant comments on valid screening tools, management strategies, what to educate on and who to educate, non-pharmacologic treatments, models of care, training or capacity-building strategies, and suggested resources were not aligned, indicating there is a lack of consensus as to what is the best approach. There was variance among participant responses on the necessity of aspects of care including prevention, identification of early warning signs, case finding, standardized interventions, and access to virtual care resources. Standardized practice was reported to be in conflict with individualized approaches to care for behaviours. The conflict between standardized and individualized approaches was noted for assessments and case finding, interventions, and training and capacity-building strategies. Topics addressing interventions, models of care, and virtual resources were identified by some participants as being too big or broad to be addressed in the guideline. Topics addressing early warning signs and models of care were perceived by some participants to lack the available evidence required to address the topic.

New Topics

Participants identified new topics for the current guideline to be considered for inclusion. The topics were thematically grouped to produce the following ten themes: accessing resources, ‘intersections between dementia pathology, stages, delirium and palliative care’, caregiver skills/training/support,

TABLE 2.
Participants’ responses to include or exclude the seven research team-identified topics in the current guideline

Topic	*Total Number of Respondents*	*Include in Current Guideline*	*Do Not Include in Current Guideline*	*Comment Only Provided*
Topic 1 – Prevention: What are the best approaches for preventing behavioural symptoms of dementia?	225	217 (96.44%)	7 (3.11%)	1 (0.44%)
Topic 2 – Prodromal symptoms: What are prodromal symptoms or early warning signs that may increase risk of developing behaviours in dementia?	226	206 (91.15%)	16 (7.08%)	4 (1.77%)
Topic 3 – Screening: What are effective approaches to screening or case finding for behaviours in dementia?	226	199 (88.05%)	24 (10.62%)	3 (1.33%)
Topic 4 – Interventions: Which non-pharmacological, self-management, and pharmacological interventions are effective for behaviours in dementia?	227	221 (97.36%)	4 (1.76%)	2 (0.88%)
Topic 5 – Training: What are the most effective strategies for training or capacity building in the population to support care of older adults affected by behaviours in dementia?	227	204 (89.87%)	22 (9.69%)	1 (0.44%)
Topic 6 – Models of care: What are the different models of care available to support population-based prevention, promotion and care of older adults with behaviours in dementia?	228	191 (83.77%)	33 (14.47%)	4 (1.75%)
Topic 7 – Virtual care: What are available virtual or telehealth options to support delivery of best practices for behaviours in dementia?	227	187 (82.38%)	35 (15.42%)	5 (2.20%)

TABLE 3.
Overarching themes identified from participant comments on the seven research team-identified topics

Theme	*Examples*
Lack of consensus on best approach (e.g., participants provided different ideas indicating it is unclear which approach is used in practice)	Which valid screening tools exist (topic 3) Management strategies (topic 4) What to educate on and who to educate (topics 1 and 5) Non-pharmacologic treatment approaches (topic 4) Models of care (topic 6) Training or capacity building strategies (topic 5) Suggested resources (topic 7)
Disagreement on the necessity and/or ability to deliver aspects of care (e.g., participants disagreed on the capacity or ability to provide or access care)	Prevention (topic 1) Identification of early warning signs (topic 2) Case finding (topic 3) Standardized interventions (topic 4) Access to virtual care resources (topic 7)
Conflict between approaching care using standardized practices or individualized approaches to care	Assessments and case finding (topic 3) Interventions (topic 4) Training or capacity building strategies (topic 5)
Topics too broad for inclusion in guideline	Interventions (topic 4) Models of care (topic 6) Virtual care resources (topic 7)
Lack of available evidence to address topic	Early warning signs (topic 2) Models of care (topic 6)

communication strategies, equity in care for persons living with dementia, managing behaviour in general, managing overarching care needs, pharmacologic treatment concerns, non-pharmacologic treatment, and organizational issues. The suggested topics, grouped by theme are presented in Table 4.

Survey Topics Included in the Final CPG

Within the CPG, we were able to cover Topics 3 to 5 in depth, and in part Topic 6 (Table 5). Topic 1 on prevention was covered where possible, but was not a separate section in the CPG. Topics 2 and 7 were not included in the CPG. All topics were discussed in detail during the CPG development, and the decision was made to focus on screening (Topic 3), interventions (Topic 4), and training (Topic 5) as these are key aspects of clinical care and are required for the first CPG. Concerns related to Topics 1, 2, and 7 included a lack of primary evidence compared to the other topics; however, Topics 1, 2, and 7 were identified as priority topics for future CPG iterations. Overall, the guideline panel represented major clinical end-users, and the relative focus for the guideline was placed on what frontline clinicians needed most. Additionally, there were resource and time constraints which made the inclusion of all topics in the CPG not feasible.

DISCUSSION

In this survey to identify terminology and topics for guideline development, behavioural and psychological symptoms of dementia was identified as the preferred terminology for behaviours in persons living with dementia.

Participants from diverse groups completed the survey to achieve a broad perspective in responses. By engaging with end-users through the survey, the research team was able to identify topics that are meaningful and important to patients, care partners, and health-care providers. Key focus was placed on prevention, non-pharmacologic interventions, risk factors for behaviours, and training/capacity-building. Engaging end-users from the beginning of the guideline development process is critical to creating a CPG that is both applicable to end-users and addresses patient care needs.

Terminology

The preferred terminology selected (behavioural and psychological symptoms of dementia) was the term with the most votes from participants, but did not make up the majority. This was because there was a wide range of supported terminology. When preferred terminology was examined by participant role, the term “responsive behaviours” was also a popular choice amongst friend or family caregivers, health-care aides or personal service workers, educators, managers, specialized behavioural providers, allied health, and policymakers. Similar to behavioural and psychological symptoms of dementia amongst all participants, responsive behaviours was the most commonly selected option in participant role groups, but was not often represented as the majority selection.

Terminology is important when discussing BPSD as there is stigma associated with certain terms more than others. Along with this, BPSD is aligned with the research language for this group of symptoms, whereas responsive behaviours is aimed to be more person-centred language.(11,16) There are also patient, care-partner, health-care provider, and organizational preferences on language used to describe BPSD that vary. Clinically, it is more relevant to discuss the specific BSPD symptoms in the context of the patient, with a description of the relevant events and what they are experiencing. Similarly, health-care providers should enquire what persons living with dementia or their care-partners are using to describe the BPSD or the terminology they prefer to describe the symptoms. It is also key to consider how the terminology and language used may contribute to stigma or pathologize normal expressions of need. In examining the terminology for BPSD we see divergence in approaches which likely represents the difference between language used in research versus patient-centred or clinical terminology. Further, there is ongoing refinement of language as it pertains to BPSD, and preferred terms will depend on the context of the situation and preferences of the persons. What is very clear is there is a need to have respectful language when discussing BPSD, and ensure any terminology used is clear to all involved in care. There are numerous person-centred language guidelines

TABLE 4.
New topics identified by participants with participant comments as examples

Theme	*Participant Comment*
Accessing resources	How to access community resources What resources are available (e.g., treatments, community supports) Clinical practice guidelines (e.g., treatment, suicide prevention, how to describe behaviours)
Intersections between dementia pathology, stages, delirium and palliative care	Why behaviours in dementia occur How behaviours present in different types of dementia Assessing for or differentiating delirium from behaviours in dementia Standardized language Goals of care discussions, palliative approach to care, medical assistance in dying in the context of behaviours in dementia
Caregiver skills/training/support	Support, resources, and education Strategies and approaches (e.g., environmental modification, safety) Mental health of unpaid or family caregivers (e.g., self-care, supports, when to seek help, burnout) How to involve or provide information to caregivers
Communication strategies	Communication and approach strategies Enhancing communication
Equity in Care for Persons living with Dementia	Care for dementia in indigenous and LGBTQ2S communities Care for dementia in rural communities or home environment
Managing behaviours in general	How to approach and react to behaviours in dementia Individualized care approaches De-escalation techniques
Managing overarching care needs	Person/family-centered care planning Models of care guiding clinical decision-making Interventions for each behaviour Risk assessments Therapeutic approaches and meaningful engagement in activities
Pharmacologic treatment concerns	Pharmacologic approaches specific to each behaviour Tapering recommendations, required monitoring, dose, duration, polypharmacy, and deprescribing Review of all available evidence for pharmacologic treatment of different types of behaviours Threshold for initiating pharmacologic treatments Pharmacologic management based on dementia etiology Considerations related to use of antipsychotics, anxiolytics, and psychotropics
Non-pharmacologic treatment	More details on non-pharmacologic treatments Engaging allied health for meaningful non-pharmacologic activities
Organizational issues impacting care for persons with dementia	Care models (e.g., collaborative care, interdisciplinary approach, person living with dementia and caregiver involvement) Funding models Environmental contributions to behaviours (e.g., physical environment, design, living arrangements) Context-specific considerations (e.g., primary care, long-term care) How to implement guideline Staff and management (health-care provider) training

available and educational modules.(17-19) Although BPSD is the preferred term for the guideline(12) as it received the most support amongst all participants, it was not clearly supported by many participants, indicating variation remains in the preferred terminology used.

Guideline Topics

All topics identified by the research team were supported for inclusion by participants. Of interest, topics addressing models of care and virtual care resources received the highest degree of dissent for inclusion in the guideline. Participants may have indicated that these two topics should not be included in the guideline due to perceived feasibility concerns (i.e., topic was too broad or large to address in a guideline) or a perceived lack of available evidence on the topic.

Based on participant comments, it is evident there is variation on what the best approach to care is for behaviours in dementia. Participants, although agreeing on the need to address a topic, had variable responses related to the content within the topics. For example, there were concerns about the lack of validated screening tools, unclear models of care, or difficulty with effective management strategies. Further, there were concerns on how to deliver care.

Participants described how standardized care may be at odds with individualized or person-centred approaches to care for behaviours. The CPG for behaviours in dementia is based on the best available evidence, and supports the delivery of evidence-informed care. Individualized standardization may be a solution to the perceived conflict between the application of standardized guidelines and maintaining person-centred,

TABLE 5.
Survey topic alignment with final clinical practice guideline

Topics	*Included in Clinical Practice Guideline?*	*Explanation*
Topic 1 – Prevention: What are the best approaches for preventing behavioural symptoms of dementia?	No	There is no separate section on prevention of BPSD. Where able in the guideline, reference was made to any evidence for the secondary prevention of the specific behaviours noted. Along with this the Good Practice Statements highlighting the need for proactive education/training, planning, and monitoring with an aim to prevent BPSD.
Topic 2 – Prodromal symptoms: What are prodromal symptoms or early warning signs that may increase risk of developing behaviours in dementia?	No	There is no separate section on prodromal symptoms of BPSD. There is little primary research in this area as most is focused on the detection of symptoms.
Topic 3 – Screening: What are effective approaches to screening or case finding for behaviours in dementia?	Yes	Primarily discussed in Good Practice Statements 4 and 11 and in Recommendations 2, 32, 37, 50, and 56.
Topic 4 – Interventions: Which non-pharmacological, self-management, and pharmacological interventions are effective for behaviours in dementia?	Yes	Discussed in all sections of the guideline.
Topic 5 – Training: What are the most effective strategies for training or capacity building in the population to support care of older adults affected by behaviours in dementia?	Yes	Primarily discussed in Good Practice Statement 1 Also included in Good Practice Statements 7-9, Recommendations 3, 33, 51, and 56, and the CCSMH Behaviours in Dementia Toolkit online materials
Topic 6 – Models of care: What are the different models of care available to support population-based prevention, promotion and care of older adults with behaviours in dementia?	Yes, partially	There is no separate section on Models of Care. Throughout the guideline, the overarching theme of interdisciplinary teams or approaches is referenced (e.g., Good Practice Statements 1 and 8, Recommendations 3, 33, 38, and 63).
Topic 7 – Virtual care: What are available virtual or telehealth options to support delivery of best practices for behaviours in dementia?	No	There is no separate section on virtual care. It was agreed by the guideline development team that virtual care was important and would require a separate review of evidence, including the wider evidence on virtual care and computer literacy in the population as well as an environmental scan and user engagement to ensure the relevant inclusion in guideline. The guideline development team did not have the required time/resources to include virtual care in the first iteration of the guideline.

individualized care.(20) The research team produced a list of topics viewed by end-users as priorities to be addressed in the development of the CPG for BPSD; however, not all were addressed in the final guideline(12) due to resource constraints.

Final CPG Alignment with Survey Results

The CPG developed is the first Canadian guideline to address the complex issue of BPSD. Our survey aimed to help us align the CPG with what end-users need; however, the inclusion of all survey findings in the final CPG was limited by resource constraints and funding timelines. Along with resource limitations, as it was the first CPG, there was a need to include key clinical basics in the diagnosis and management of BPSD. Other important factors will be explored in the next iteration of the guideline. At the time, the CPG panel perceived that, while BPSD prevention and prodromal symptoms are important, there was minimal primary evidence to synthesize and include; thus, the panel focused on secondary prevention throughout. The management of BPSD alone was a significant focus of the CPG and, given the volume of evidence and recommendations, it was not feasible to pursue other priorities and complete recommendations in a timely and rigorous manner.

Specifically, the themes identified in Table 3 indicated a lack of consensus on approaches or disagreement among end-users on many aspects of BPSD care. For example, participants in the survey noted there was a lack of clarity on which detection tools were valid and how to use detection tools or, similarly, which non-drug management approaches should be used. These disagreements are part of the primary rationale in needing a CPG, and the research team aimed to address as many of these areas of uncertainty in the CPG as possible. It was also noted by survey participants that certain topics, such as prodromal symptoms or models of care, were either too broad or lacked evidence for inclusion in a CPG at the time of creation; these factors were taken into account when prioritizing the topics for CPG inclusion.

Many of the new topics added by participants in Table 4 are significant, and some of them we were able to address in the CPG (e.g., non-drug treatments) or related Knowledge Translation materials in the Behaviours Toolkit.(21) For example, caregiver training and communication strategies are covered extensively in the Behaviours Toolkit. Other issues, such as those around equity, need focused reviews of evidence and careful and engaged examination for inclusion in future CPG iterations. In other instances, some issues around organizational considerations or how to access resources are beyond the scope of a national CPG.

Limitations

As with any survey, we are limited to our respondents and the pools of recruitment mentioned above. Due to our virtual sampling strategy, we were unable to calculate a response rate because we could not determine the denominator or how many eligible participants received the invitation to participate. We were able to recruit a wide range of participants across Canada in many roles and age groups. Despite wide dissemination and high recruitment, we had few persons with lived experience of dementia (n=3), few over age 75 (n=7), and few who identified their gender outside of binary woman/man (n=3). Ontarians made up the largest pool of participants (n=177), with the least from Maritime provinces and Northern territories. Although there were groups with few participants, without an understanding of the base population reached through survey recruitment, it is not possible to comment on how representative survey respondents were of the true population. Nonetheless, future work should expand on these under-represented populations. Use of a convenience sample and virtual recruitment, as well as the two-month window for completion of the survey, may have limited the number and diversity of eligible participants reached. Potential selection and/or response bias may have impacted the generalizability of survey findings, where the survey results reflect the perspectives only of respondents, which may not be representative or generalizable to all CPG end-users.

CONCLUSION

Priority guideline topics were identified by end-user groups that will be impacted by the content within the CPG addressing behaviours in dementia. Participants largely agreed on the inclusion of topics presented, and identified new topics aligned with existing topics. Content related to the delivery of care for behaviours in dementia may not currently be widely agreed upon. Identifying priority topics and gauging understanding of topic area content will facilitate the targeted development and delivery of the CPG for behaviours in dementia.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal*'s policy on disclosing conflicts of interest and declare that we have none.

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SUPPLEMENTARY MATERIALS

Supplemental material linked to the online version of the paper (https://doi.org/10.5770/cgj.29.914):

- **Appendix S1:** Survey questions provided to participants
- **Appendix S2:** Preferred terminology based on all participant responses

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