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Motivations of family advisors in engaging in research to improve a palliative approach to care for persons living with dementia: an interpretive descriptive study

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Abstract

Background A Strategic Guiding Council (SGC) was created within a Family Carer Decisions Support study, to engage family carers of persons with advanced dementia as advisors to inform the design and implementation of the study. The SGC consists of an international group of family advisors from Canada, the Republic of Ireland, the United Kingdom, the Netherlands, and the Czech Republic. There are limited studies that have explored the integration of Patient and Public Involvement (PPI) in dementia research, end-of-life care and long-term care. Therefore, this study explores PPI engagement in health research with family carers to understand further their interest in being involved in the SCG within the FCDS intervention which is focused on supporting caregivers to make decisions about end-of-life care for residents with advanced dementia.

Methods This study utilized an interpretive descriptive design and explored the motivations of ten family advisors from Canada, the Republic of Ireland, the United Kingdom, and the Netherlands in being part of the SGC. Semi-structured interviews were conducted by phone or videoconferencing and were recorded, transcribed, and analyzed using thematic analysis.

Results Three themes generated from the findings of the study were (1) engaging in reciprocal learning; (2) using lived experience to support other family carers; and (3) creating a collective momentum for advocacy and change.

Conclusions Family carers motivations to being part of the SCG was driven by their intent to help carers navigate the health system and to create a psychosocial support system for other carers experiencing end-of-life with their loved ones. Being part of the SCG provided a benefit to family carers which provided a venue for them to contribute meaningful information from their experience, learn from other health professionals, research and other advisors and an avenue for advocacy work to improve access to end-of-life care supports through education. To our knowledge, this is the first study that explores the motivations of an international group of family advisors' engagement in health research to promote integration of a palliative approach to dementia care in long-term care homes. This study further

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contributes to the literature from an international perspective the importance of PPI in research. Further research is warranted that explores PPI in research to improve access to end-of-life supports.

Plain English summary

Patient and public involvement (PPI) in research has been growing worldwide and ensures that research conducted is relevant to the needs of patients. Within the Family Carer Decisions Support study, we created a Strategic Guiding Council (SGC) to engage family carers of persons with advanced dementia as advisors to improve access to a palliative approach to care. The SGC includes family advisors from Canada, the Republic of Ireland, the United Kingdom, the Netherlands, Italy and the Czech Republic. The goal of the strategy was to engage with family advisors in research activities to improve access to a palliative approach and quality of care provided to people with dementia receiving end-of-life care. Including patients and family in research is extremely important, therefore our aim in this study was to explore family advisors' motivations to engaging in the SGC. Family advisors reported encountering challenges with navigating the health system with end-of-life care and they chose to participate in the SGC to support other carers who are experiencing a similar situation. Being part of the SGC also provided the family advisors with an avenue to advocate on the importance of improving access to end-of-life supports and the opportunity to learn from other advisors, health professionals and researchers.

Keywords Patient oriented research, Palliative care, End-of-life care, Dementia, Long-term care

Introduction

Patient and Public Involvement (PPI) in research has been growing internationally due to efforts to ensure that health research is relevant, meaningful and impactful for patients and the public [1]. PPI ensures studies are focused on patient-identified priorities and encourages patients and their family/friends to be proactive partners in all stages of the research process: study design, intervention implementation, interpretation and developing of findings and knowledge translation [2, 3]. PPI values a person's lived experience and reported benefits include improvement in patient experiences, high quality health care and ensuring research funding is allocated to studies that are relevant and deemed a priority to patients and the public [4, 5]. Most importantly, PPI ensures that work is being carried out with or by members of the public, rather than for them or about them.

The inclusion of PPI in health research has been deemed a priority in many countries [6]. The United Kingdom has made PPI participation a requirement to increase community involvement in health service planning and decision making in the delivery of health initiatives and research [6]. Similarly, in Canada, the Canadian Institute for Health Research (CIHR) developed partnerships with funding agencies to develop a Strategy for Patient-Oriented Research to improve health outcomes by promoting the engagement of patients and focusing on priorities identified by patients [7]. PPI has been studied in stroke care [8], dialysis [9], mental health research [10] and has been growing within dementia research [11]. Findings from the Bethell et al. (2018) scoping review discussed the importance of collective learning from people with lived experience with dementia and reinforced the importance of challenging societal views that portray people with dementia as not fully capable of participating

in research [11]. Although there is broad consensus on the importance of integrating PPI in health research, further research is warranted to explore the integration of PPI in dementia research, long term care (LTC) and end-of-life care to improve health outcomes for older adults living with dementia and their family carers through meaningful engagement in health research.

In order to improve the quality, relevance and uptake of research amongst family carers, PPI engagement was integrated within the Family Carer Decision Support (FCDS) mySupport study [12–14]. The FCDS intervention focused on supporting caregivers to make decisions about end-of-life care for residents with advanced dementia. Introducing a palliative approach to care promotes a comprehensive person-centered approach to care for residents during end-of-life through advance care planning, management of disease symptoms, psychosocial and spiritual care and bereavement support [15]. The FCDS study was implemented in Canada, the Republic of Ireland, the United Kingdom, the Netherlands, Czech Republic, and Italy during the COVID-19 pandemic. An international PPI panel, called The Strategic Guiding Council, was formed early on to help inform the design, implementation and evaluation of the FCDS intervention by advising the research team and sharing their experiences in caring for individuals living with advanced dementia in LTC. There were 15 people involved in the Strategic Guiding Council. These individuals met via Zoom at quarterly Strategic Guiding Council meetings. They were involved in reviewing draft intervention components such as the comfort care booklet, providing assistance in interpreting study findings, and offering recommendations for knowledge translation and dissemination activities [16, 17].

To our knowledge, there are currently no research studies that have explored PPI engagement in health research within an international Strategic Guiding Council. In addition, there is little information in the literature that discusses how to engage and involve families in LTC research [18, 19]. Meaningful engagement with family carers is an important area to focus on in research as it provides researchers with a unique perspective of their lived experience which can also lead to an improvement in research questions, facilitate knowledge transfer and promote trust [18, 20]. Therefore, this qualitative study aimed to contribute to the literature on PPI engagement with family carers by exploring the motivations of family carers to become family advisors on the Strategic Guiding Council. It is imperative to explore the motivations of family carers in research for recruitment and retention purposes as they are important members of the research team who can provide feedback on the practicality and relevance of interventions. The research question was: What are family advisors' motivations in working with a Strategic Guiding Council and research team to promote integration of a palliative approach to dementia care in LTC homes?

Methods

Design

This study utilized Sally Thorne's (2016) interpretive description methodology to address the research question. Interpretive description is grounded in a naturalistic inquiry and objective knowledge is unattainable through empirical analysis but rather, the participants and researcher construct meaning together [21]. Interpretive descriptive is known as a useful methodology to generate knowledge for health service research due to its focus on experiential knowledge and exploring human commonalities and differences [21]. This approach was suitable for this study to reflect on the diverse experiences of family carers in supporting persons living with dementia which shaped their motivations to engage in research as family advisors.

Sampling

Convenience sampling [22] was used to locate participants who were interested in being a member of the Strategic Guiding Council to advise the FCDS study and share their viewpoint as family carers for individuals living with advanced dementia. Specifically, they met the following inclusion criteria: (a) family carer of a person with advanced dementia (living or passed away in the last five years); (b) 16 years of age or older; and (d) comfortable communicating in English.

Recruitment

Recruitment for the Strategic Guiding Council consisted of both passive and active recruitment strategies. We attempted to recruit participants from all six countries involved in the FCDS intervention, however we were unable to recruit family carers from Italy and the Czech Republic due to language barriers. Hence, we ended up with family carers from four of the six participating countries: Canada, United Kingdom, the Republic of Ireland and the Netherlands. The recruitment of family advisors to join the Strategic Guiding Council and research study was conducted through the completion of an Expression of Interest Form and country-specific recruitment flyer, which were posted at local organizations (i.e., LTC homes) for a period of two months between June to August 2020. The Expression of Interest Form and the Country-Specific Recruitment Flyers were also posted on the mySupport website. Family carers who were interested in participating in the Strategic Guiding Council completed the Expression of Interest Forms and once completed, the PPI study coordinator, along with the country-specific research representative, contacted eligible individuals who met the inclusion criteria.

Active recruitment strategies for the study consisted of staff working in LTC homes or nursing homes to share information to family carers regarding the Strategic Guiding Council and mySupport study following a recruitment script guideline developed by the research team. Verbal permission was sought from the family carers to have their contact information shared with the research team to discuss the Strategic Guiding Council and mySupport study further. A telephone or email recruitment script was used by research staff to inform interested family carers about the study, answer any questions and affirm their continued interest to participate. Family carers that provided consent to be part of the Strategic Guiding Council as family advisors were provided with an orientation, which was conducted by the PPI coordinator or the country-specific research representative either in-person or virtually. Two family advisors were included in this manuscript as co-authors as they contributed to writing and reviewing the manuscript.

Data collection

Demographic data such as country of residence, sex, age, and relationship to person living with dementia were collected electronically using LimeSurvey. Semi-structured interviews were conducted by the PPI coordinator or by the country specific research representative either on the telephone or Zoom videoconference platform based on participants' preference from September 2020–2021. The interviewers were master's prepared or graduate students in the field of nursing and health studies. Interviews were scheduled based on their preference for time

in their respective time zones and within the first three months of joining the Strategic Guiding Council. Interviews were conducted in English and the country specific research coordinator was available to assist participants with translation support as a 'buddy'. Participants took part in an interview in a quiet, private location of their choosing such as in their home. An interview guide was used to explore family carers' motivation in working with a Strategic Guiding Council and research team and developed through a review of the literature for PPI concepts. Examples of interview questions were: What is your experience with palliative care? What is your experience working with research and what about your experience working on a panel or a committee? What is your understanding of a Strategic Guiding Council? The interviews lasted 30 to 40 min and were audio-recorded and transcribed verbatim. Identifying information was removed and transcripts were reviewed against the recording for accuracy [23]. Participants' identity was protected throughout the study and all study information that was recorded, transcribed and analyzed were kept in a locked cabinet or stored in a password protected, encrypted file.

Data analysis

Demographic data were analyzed using counts for categorical data and means and standard deviations (SD) for continuous data. The first stage of data analysis consisted of "sorting and organizing" [21 pp 156] the data by reading the transcripts. In the second stage, "making sense of pattern" [21 pp 163], the authors (SL and JK) analyzed two transcripts independently and generated a code list and themes. The authors (SL and JK) met together and discussed their preliminary findings. Descriptive codes were merged to develop themes or groupings [21]. The findings were then discussed with additional research team members (SV, VM and SK) and themes were defined based on consensus. Once consensus was gained within the research team, SL proceeded with analyzing the remaining transcripts using Dedoose qualitative software. For the final stage, "transforming pattern into findings" [21 pp 173] the author SL met frequently with the research team during data analysis to review the findings and themes generated. The final written conceptualization of the findings was reviewed by the research team and presented in this study [21].

Ethical considerations

This study was approved by local research ethics board (#5837). Research was conducted following the standards outlined by the Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans [24]. Written and verbal informed consent was sought from all participants with the understanding that their participation in the study would not influence them or their relatives

care at the LTC home. Each participant had experience as a family carer for a relative with dementia and due to this, were sensitive to emotional reactions. Therefore, the sensitive interviewing techniques were employed, which included validation of emotions and experiences of the interviewer, frequent breaks and if needed, discontinuation of the interview.

Rigour and trustworthiness

Several strategies were employed by the research team to enhance trustworthiness and rigour in the study. The research team participated in co-constructing knowledge by interpreting participants experiences from the semi-structured interviews. Researcher triangulation was achieved by meeting frequently with the research team to discuss data analysis and themes developed. Engaging in triangulation allowed the researcher to confirm constructed perception of an event or process [21]. An audit trail was maintained by the primary author to establish confirmability of the research findings and ensure the findings are based on participants responses instead of the researchers' own preconceptions and biases.

Results

Characteristics of sample

A total of 10 family advisors shared their perspectives in being part of the Strategic Guiding Council for the mySupport Family Carer Decision Support Study. There was representation from four countries, Canada ($n=4$), United Kingdom ($n=1$), the Netherlands ($n=1$), and the Republic of Ireland ($n=4$). Demographics were missing for some advisors ($n=5$). Half of the advisors were female ($n=5$). The mean age of advisors was 65.6 years ($SD=5.0$) and most were caring for a spouse or parent. Most of the advisors reported having education at the post-secondary level (i.e., college, bachelor's degree, masters).

Overview of findings

Three themes represented the family advisors' motivation in engaging with the Strategic Guiding Council: (1) *engaging in reciprocal learning*; (2) *using lived experience to support other family carers*; and (3) *creating a collective momentum for advocacy and change*.

Theme 1. Engaging in reciprocal learning

This first theme explains how family advisors were motivated to be engaged with the Strategic Guiding Council and research team to help and also learn about health and social services from other care partner experiences. This was identified by one advisor who shared: "I have experiences that might be valuable, but other people on the council may have experiences that could help me as well" (P2, Canada). A family advisor expressed that engaging with health professionals on the research team (e.g.,

nurses, physicians, social workers) allowed for reciprocal learning, where the care partner learned from the health professional and the health professional had the chance to learn from caregivers:

I also very much enjoy the interaction of working with professionals [health]. I love the learning experience that both of us can get and ultimately again as we discussed before, what I learn I can then take back to the people who can gain the most from what I learn. Which are the people suffering the condition. (P5, United Kingdom)

By engaging with the Strategic Guiding Council, participants mentioned that it provided them with the opportunity to learn about interventions and programs that are happening in other countries. Family advisors further endorsed that being involved with the Strategic Guiding Council, not only did it promote reciprocal learning between the caregiver and healthcare team, it also allowed family advisors to be active participants in their loved one's care and not "only visitors" (P6, The Netherlands).

Theme 2. Using lived experience to support other family carers

This theme describes the participants' lived experience as a family carer of a person with dementia and how their experience was a driver for engaging with the Strategic Guiding Council. Based on their own experiences, family advisors expressed a strong desire to create a circle of moral and psychosocial support system for other carers. Advisors endorsed that their personal experience with a loved one gave them "the drive to do something" (P10, the Republic of Ireland). This revealed how they reflected on their previous experiences in supporting persons with dementia to inform necessary changes for other family carers. The advisor further elaborated: "I thought for anybody that's going through it, you know I'm going to try and do something to help improve this". This sentiment was further expressed by another participant:

I think just giving my personal experience that I've had in Long Term Care. I watched how my father lived and how his end of life was and just want to help in any way that I can for other families going through such a difficult time. (P1, Canada)

Family advisors expressed experiencing challenges with obtaining appropriate end-of-life care for their loved one due to clinicians working in care homes limited knowledge regarding a palliative approach to care, which contributed to negative experiences. One participant mentioned, "My mom's GP [general practitioner] denied

her Palliative Care because he said she didn't have Cancer" (P9, The Republic of Ireland). The advisor further attributed that the lack of information from the physician led to feelings of frustration but then 'sparked something within', which led the participant to determine that: "rather than fighting the system, I educated myself. I just decided I would speak out and tell mom's story to change those mistakes and hopefully make a difference" (P9, The Republic of Ireland)

Another advisor expressed a similar situation where she experienced challenges with her husband receiving adequate pain management despite advocating on his behalf to stakeholders in his long-term care home and physician. The advisor shared:

With my husband, the home didn't know anything about Palliative Care and we became increasingly desperate because he was having such terrible pain. Awful pain, and it was just awful to see his body twisting. I was so desperate. I tried to get him into a hospice and they had no beds and I turned to the Palliative Care nursing team that cover residents around the country side and towns. They said they can't come in and help unless they are asked to by the GP that covers the residential home and I asked him [GP] and he wouldn't speak to me. (P5, United Kingdom)

After advocating on behalf of her husband for adequate end-of-life care, the advisor further shared:

It was only the day before he died that he was completely pain free. The last few days of his life he had some pain control. That shouldn't have happened, he should have had pain control months before, or weeks before he became in such a terrible state. That's why I'm desperate that it doesn't happen to other people. (P5, United Kingdom)

Although many family advisors shared negative experiences with end-of-life care, an advisor described end-of-life care as a "beautiful, worthwhile thing to be a part of" (P2, Canada). She further describes how end-of-life care has been a large part of her life since she was a caregiver to family members who passed away in LTC. Therefore, she hopes to be able to help others going through a difficult moment by sharing her experience:

It's worthwhile to be able to share the things you know and share your experience with families to have when they are facing this end-of-life care phase. It's a really difficult circumstance to be in and it's very complex it's nothing that you can rehearse for...

I think that my experience could be valuable to other people. (P2, Canada)

A strong motivating factor that led advisors to engage with the Strategic Guiding Council and research team was to help others navigate the health system. Advisors expressed encountering challenges navigating the health system to ensure that their family member with dementia was provided with the treatment that they needed. Many endorsed a motivation to be engaged with the Strategic Guiding Council was to help other caregivers navigate the health system. An advisor shared: "I think it is in helping people find their way through different systems ... as they begin to navigate it and know the important things to look for and what things to just let go" (P4, Canada).

In addition, an advisor also learned from her experience that it is important to seek help early on and engage in discussions about dying early on in a person's care until they are at the end-of-life. She shared:

My mission is that what happened to my husband never happens to other people. They get to that stage and understand and get help quickly ... definitely get help early on and leave it sort of until its Palliative and it can't be controlled. They need to know earlier on. (P5, United Kingdom)

A family advisor further described supporting a family member with dementia as the power of attorney and described the process as not black or white. The advisor disclosed the challenges and complexities of being power of attorney, especially in relation with capacity of understanding concerns. Supporting families navigate these concerns was a motivating factor for the advisor to join the Strategic Guiding Council. One advisor expressed: "To think that I could help family members understand what might be ahead of them, I thought was interesting and useful...so that was the motivation" (P8, The Republic of Ireland). Overall, participants identified the importance of sharing their knowledge and experience as a means of enlightening others and helping other carers in their caregiving journey.

Theme 3. Creating a collective momentum for advocacy and change

This theme describes the importance of advocacy to improve access to palliative care supports and education to reduce stigma in end-of-life care. Family advisors are motivated to be engaged with the Strategic Guiding Council to be able to use their voice to improve the quality of care provided to individuals with dementia and use their voices to "support or influence the direction of the program (P7, The Republic of Ireland). An advisor shared:

Advocate for elderly people to have Comfort Care, even if it is not in the last part of their lives. They have to have Comfort Care even when the disease of Dementia comes, to have all the people around you and try to make the life of the person as comfortable as can be. (P6, The Netherlands)

An advisor shared how being involved in their loved ones care brought fulfillment in their life through the advocacy work they are engaged in:

I look back now and I think it's probably the best thing I have achieved in my life. Plus, it's opened up my world to meeting amazing people. Like even now talking to you today [researcher], like if mom hadn't come into my life, I wouldn't be doing any of this [advocacy]. I don't know what I'd be doing but I certainly wouldn't be worrying about Dementia and end of life or having anything to do with it. It's completely the opposite to what my life was. (P9, The Republic of Ireland)

Despite programs developed to bring more awareness regarding dementia care, advisors endorsed that there is still stigma that exists regarding dementia.

I don't know about other countries but in the Republic of Ireland there's not as much of a stigma as there was but there's definitely still a stigma around Dementia or Alzheimer's. There's definitely huge education needed for the general public as well. It's getting better. People are more aware, as well as there are more supports. But there's still ... you know, it's one of those things that some people don't want to talk about. (P10, The Republic of Ireland)

The Strategic Guiding Council was identified as an opportunity for advisors to be engaged in research initiatives and cross-country collaborations to improve integration of a palliative approach to care for individuals with dementia. An advisor who also had a long career in research shared:

I like the idea that it's an international project and it will be interesting to see what the results are and also to make a difference for families that have family members or friends who have Dementia and reach end of life. It would be nice to make a difference if we can somehow. I like fairly efficient things, but I want to see some real impact you know collectively from this research project. I've been doing research for forty-five years so I know that lots of things take a long time to make a difference but I'd

like to see some real outcomes from the research. (P3, Canada)

Through engagement in the Strategic Guiding Council and research team, a collective momentum for change can be made to improve the care being provided to people with dementia and provide person-centered care. An advisor emphasized the importance for health professionals to explore the wishes of the person with dementia and their family members to improve quality of life:

The nurses and the staff must be aware of the wishes of patients and family of the patients so they can be part of the last few times [moments] of the patient's life and try to make it more about the person and family want to have and not the wishes of the organization to be efficient. (P6, The Netherlands)

Discussion

This study sought to explore the perspectives of family advisors' motivations in working with a Strategic Guiding Council and research team to promote integration of a palliative approach to improve dementia care in LTC homes. To our knowledge, this is the first study which explores the perspectives of family carers motivations to participate in PPI research in an international Strategic Guiding Council, from four participating countries (Canada, United Kingdom, Republic of Ireland, and the Netherlands). The Strategic Guiding Council international study provided the advisors with an opportunity to be engaged in cross-country collaborations to improve end-of-life care for individuals with dementia and support the research team in determining opportunities to improve patient and family engagement.

The study findings are relevant to healthcare as it provides the perspectives of family carers motivation in being partners in care and research, which is an area of research that requires further exploration in LTC settings [18]. Involving family and patients in the development and implementation of research, enriches the relevance of the study by generating interventions that are sustainable and translatable to the community of interest [25]. PPI involvement is a growing area in health research and ensures that research is conducted in a manner that is relevant and meaningful to patients and the public [26, 27]. Warner et al. [28] emphasizes the importance of involving patients and families in their care to ensure care reflects their needs and values. Through patient and family integration in the planning process, it can lead to positive patient end-of-life and family bereavement outcomes [28].

Family advisors in the study discussed how their lived experience providing care for a person with dementia

was a motivating factor to wanting to be engaged with a Strategic Guiding Council and research team. Participants wanted to use their experience to help others who are going through difficult situations. Similar to the findings in our study, a study conducted by Cashin et al. [29] explored family's motivation to being engaged in research and education development with health professionals, which was driven by their desire to improve their knowledge and promote awareness of dementia. Findings from the study are also consistent with family centered research that has been conducted in different disciplines. O'Keeffe et al. [30] explored family members motivation to being engaged in research in the field of adolescent mental health. A commonly cited motivation for being engaged with a research team was a desire to help others going through similar difficulties [30].

Advisors in the study discussed challenges with obtaining appropriate referral for end-of-life care or palliative treatment (i.e., pain management) for their loved one which was a driver for them to want to be engaged in a Strategic Guiding Council. Advisors reported stakeholders in care homes and health professionals limited knowledge regarding a palliative approach to care as a reason for experiencing challenges with obtaining a referral or treatment. This finding is consistent in the literature which discusses the need to expand education on end-of-life care amongst health professionals of all disciplines, patients and family [31–33]. In a study from Bolt et al. [34], the author emphasizes that nurses who provide care to people with dementia have a crucial role in identifying end-of-life needs and observing changes in clinical health status due to their frequent interactions with residents. However, it is imperative to explore effective education opportunities to promote capacity building within health professionals working in long-term care homes to provide a palliative approach to care to improve the health service delivery of older adults receiving end-of-life care.

PPI research is critical and it is imperative that researchers aim to achieve actionable outcomes with the participation of patients and public participation in research [11]. Advisors in the study disclosed how they want to be involved with the research team to be able to 'see some real impact' from the research projects they are engaged with. In a systematic review conducted by Domecq et al. [35], patient engagement in the planning and execution of research may improve its translation into clinical practice and may yield meaningful reports that's written in a language that is understandable for participants and the community, thus supporting knowledge translation. Increasing participatory action research amongst patients and family to improve end-of-life care and dementia care may improve a person's quality of life through the inclusion of individuals with lived experience to make program improvement recommendations [11].

Thus, reinforcing the importance of an interdisciplinary and unified approach to research.

Results from this study generated implications for research, policy, and practice. Research and policy implications generated from the study further emphasizes the importance of ensuring PPI is integrated in LTC settings and international research projects to further improve the implementation of a palliative approach to care within nursing homes and improve the quality of life of residents in the late phase of their illness. Advisors in the Strategic Guiding Council supported the FCDS study and were actively involved in creating guides for families and education materials along with the research team. Practice implications from the study reinforces the importance of involving family members in the decision-making process of their loved one's goals of care during end of life. Families who are not provided the opportunity to discuss their relative's illness, prognosis, and treatment experience difficulties with decision-making processes, feel uncertainty about the illness and may also feel unprepared for their relative's death [31]. Exploring the motivations of family carers allowed the research team to engage family carers meaningfully by ensuring that their perspectives and lived experiences were incorporated in the FCDS research study. In addition, this study further contributes to the limited body of literature that explores PPI research amongst family caregivers in LTC [18, 19].

Strengths and limitations

A major strength of this study is that the Strategic Guiding Council includes advisors from four countries with unique contexts with regards to healthcare systems and available services and presents findings PPI research within an international team. Additional study strengths include strategies to enhance trustworthiness of the study findings which consisted of meeting with the research team to engage in debriefing to ensure reflexivity and conformability with the research findings. The authors in the study also utilized triangulation to ensure rigour, which allowed for the confirmation of the findings and different perspective with the phenomena of interest [36]. Despite the research study utilizing a small sample of individuals from participating countries, this study offered an international perspective that explored the motivation of family advisors' in working with a Strategic Guiding Council and research team which has not been explored before. Future qualitative research could include a large sample size and more countries beyond Canada and Europe. Advisors had to be comfortable in speaking in English, however a 'buddy' such as a research coordinator was assigned to those who required some translation. Despite the use of a 'buddy', due to limited time and resources we were unable to recruit family advisors in Italy and Czech Republic. Therefore, we were unable to

include advisors in the study due to their limited proficiency in English. Future research should have measures in place to allow participants to take part in interviews in the language of their choosing. This study was also conducted during the COVID-19 pandemic and therefore future research should explore the impact of the pandemic with family caregivers' participation in research. Additionally, the findings reinforce that family caregivers are motivated to be active participants in their loved ones care and want to be involved in meaningful work through research engagement. Therefore, researchers should aim to explore further family caregivers role in research to support in recruitment and to conduct meaningful research to improve health service delivery for patients.

Conclusion

This study contributed to the enrichment of literature by exploring PPI in research from an international perspective. Motivations that led to engagement with the Strategic Guiding Council and research team consisted of family advisors' using lived experience to support other family carers and the motivation to engage in reciprocal learning with other care partners and research professionals. While many Family Advisors had strong motivations to be engaged with the Strategic Guiding Council and research team, many endorsed aspirations to support care partners navigate through the complexity of the health system and create a collective momentum for advocacy and change to improve end of life dementia care through their involvement with the Strategic Guiding Council.

Abbreviations

PPI	Patient and Public Involvement
SGC	Strategic Guiding Council

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-024-00623-w>.

Supplementary Material 1

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Author contributions

SK is the principal investigator of the study. SL, JK, SV, VM and SK were involved in data analysis. SL and ML drafted the initial version of the manuscript. All authors (SK, SL, ML, JK, SV, VM, BT, PH, CG, DJ, TS, RG) have read, made critical revisions, and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study was approved by local research ethics board (#5837). Written and verbal informed consent was sought from all participants prior to engaging in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. L'Esperance A, O'Brien N, Gregoire A, Abelson J, Canfield C, Del Grande C, Dogba MJ, Fancott C, Levasseur MA, Loignon C, Majnemer A, Pomey MP, Rasiah J, Salsberg J, Santana M, Tremblay MC, Urquhart R, Boivin A. Developing a Canadian evaluation framework for patient and public engagement in research: a study protocol. *Res Involv Engagem*. 2021;7(1):10. <https://doi.org/10.1186/s40900-021-00255-4>.
2. Burgers JS, van der Weijden T, Bischoff EA. Challenges of research on person-centered care in general practice: a scoping review. *Front Med*. 2021;8(669491). <https://doi.org/10.3389/fmed.2021.669491>.
3. Burns KK, Bellows M, Eigenseher C, Gallivan J. Practical resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC Health Serv Res*. 2014;14(175):1–15. <https://doi.org/10.1186/1472-6963-14-175>.
4. Holroyd-Leduc J, Resin J, Barwich D, Elliot J, Huras P, Legare F, Mahoney M, Maybee A, McNeil H, Pullman D, Sawatzky R, Stolee P. Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making and in health policy. *Res Involv Engagem*. 2016;2(23):1–19. <https://doi.org/10.1186/s40900-016-0038-7>.
5. Patrick K, Kebbe M, Aubin D. A home for patient-oriented research. *CMAJ*. 2018;190(20):E607. <https://doi.org/10.1503/cmaj.180587>.
6. South J, Fairfax P, Green E. Developing an assessment tool for evaluating community involvement. *Health Expect*. 2005;8(1):64–73. <https://doi.org/10.1111/j.1369-7625.2004.00313.x>.
7. Canadian Institute of Health Research. Strategy for patient-oriented research. [internet]. <https://cihr-irsc.gc.ca/e/41204.html> (2022). Accessed 4 Jan 2022.
8. Loud F, Jain N, Thomas N. How to develop a patient and carer advisory group in a quality improvement study. *J Ren Care*. 2013;39(2):1–9. <https://doi.org/10.1111/j.1755-6686.2013.12032>.
9. Jun M, Manns B, Laupacis A, Manns L, Rehal B, Crowe S, Hemmelgarn BR. Assessing the extent to which current clinical research is consistent with patient priorities: a scoping review using a case study in patients on or nearing dialysis. *Can J Kidney Health Dis*. 2015;2(35). <https://doi.org/10.1186/s40697-015-0070-9>.
10. Fox S, FitzGerald C, Denning KH, Irving K, Kernohan WG, Treloar A, Oliver D, Guerin S, Timmons S. Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. *BMC Palliat Care*. 2018;17(1):1–11. <https://doi.org/10.1186/s12904-017-0221-0>.
11. Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, Wighton MB, Hammell J, Doyle E, Nadeau S, McGilton KS. Patient engagement in research related to dementia: a scoping review. *Dementia*. 2018;17(8):944–74. <https://doi.org/10.1177/1471301218789292>.
12. Bavelaar L, Visser M, Walshe C, Preston N, Kaasalainen S, Sussman T, Cornally N, Hartigan I, Loucka M, di Giulio P, Brazil K, Achterberg WP, van der Steen JT. The impact of the mySupport advance care planning intervention on family caregivers' perceptions of decision-making and care for nursing home residents with dementia: pretest–post-test study in six countries. *Age Ageing*. 2023;52(3):1–9. <https://doi.org/10.1093/ageing/afad027>.
13. Harding AJ, Doherty J, Bavelaar L, Walshe C, Preston N, Kaasalainen S, Sussman T, van der Steen JT, Cornally N, Hartigan I, Louka M, Vlckova K, Di Giulio P, Gonella S, Brazil K. A family carer decision support intervention for people with advanced dementia residing in a nursing home: a study protocol for an international advance care planning intervention (mySupport study). *BMC Geriatr*. 2022;22(1):1–10. <https://doi.org/10.1186/s12877-022-03533-2>.
14. Brazil K, Walshe C, Doherty J, Harding AE, Preston N, Bavelaar L, Cornally N, Di Giulio P, Gonella S, Hartigan I. Implementation of an advance care planning intervention in nursing homes: an international multiple case study. *Gerontologist*. 2024;gnae007. <https://doi.org/10.1093/geront/gnae007>.
15. Vellani S, Maradiaga VR, Nicula M, Lucchese S, Kruizinga J, Sussman T, Kaasalainen S. Palliative approach to care education for multidisciplinary staff of long-term care homes: a pretest post-test study. *Gerontol Geriatr Med*. 2023;9:1–9. <https://doi.org/10.1177/23337214231158470>.
16. Bavelaar L, McCann A, Cornally N, Hartigan I, Kaasalainen S, Vankova H, Di Giulio P, Volicer L, Arcand M, van der Steen JT, Brazil K. mySupport study group. Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15 year timespan. *BMC Palliat Care*. 2022;21(1):76. <https://doi.org/10.1186/s12904-022-00962-z>.
17. Bavelaar L, Nicula M, Morris S, Kaasalainen S, Achterberg WP, Loucka M, Vlckova K, Thompson G, Cornally N, Hartigan I, Harding A, Preston NJ, Walshe C, Cousins E, Harrison-Dening K, Devries K, Brazil K, van der Steen JT.

- Developing Country-specific questions about end-of-life care for nursing home residents with Advanced Dementia using the nominal group technique with Family caregivers. *Patient Educ Couns*. 2022;105(4):965–73. <https://doi.org/10.1016/j.pec.2021.07.031>.
18. Yous ML, Connelly DM, Zhuang R, Hay ME, Garnett A, Hung L, Snobelen N, Gao H, Criferg K, Furlan-Craievich C, Snelgrove S. Perceptive responses and familiar staff facilitate meaningful engagement of older adults and family/care partners in long-term care home implementation science research during COVID-19. *Patient Experience J*. 2023;10(2):138.
 19. Hung L, Berndt A, Wallsworth C, Horne N, Gregorio M. Involving patients and families in a social robot study. *Patient Experience J*. 2019;6(2):66–74. <https://doi.org/10.35680/2372-0247.1362>.
 20. Allard J, Ballesteros F, Anthony SJ, Dumez V, Hartell D, Knoll G, Wright L, Fortin MC. What does patient engagement mean for Canadian national transplant research program researchers? *Res Involv Engagem*. 2018;4(13). <https://doi.org/10.1186/s40900-018-0096-0>.
 21. Thorne S. Interpretive description: qualitative research for applied practice. 2nd ed. Routledge. Crossref; 2016.
 22. Robinson OC. Sampling in interview-based qualitative research: a theoretical and practical guide. *Qual Res Psychol*. 2014;11(1). <https://doi.org/10.1080/14780887.2013.801543>.
 23. Patton MQ. Qualitative research and evaluation methods. 4th ed. Washington, DC: Sage; 2015.
 24. Canadian Institute of Health Research. Tri-council policy statement: Ethical conduct for research involving humans. [internet]. <https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf> (2018). Accessed 4 Jan 2022.
 25. Kwon SC, Tandon SD, Islam N, Riley L, Trinh-Shevrin C. Applying a community-based participatory research framework to patient and family engagement in the development of patient-centered outcomes research and practice. *Transl Behav Med*. 2018;8(5):683–91. <https://doi.org/10.1093/tbm/ibx026>.
 26. Miah J, Parsons S, Lovell K, Starling B, Leroi I, Dawes P. Impact of involving people with dementia and their care partners in research: a qualitative study. *BMJ Open*. 2020;10(e039321). <https://doi.org/10.1136/bmjopen-2020-039321>.
 27. Shippee ND, Garces JP, Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin PJ, Montori VM, Murad MH. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect*. 2013;18(5):1151–66. <https://doi.org/10.1111/hex.12090>.
 28. Warner G, Baird LG, McCormack B, Urquhart R, Lawson B, Tschupruk C, Christian E, Weeks L, Kumanan K, Sampalli T. Engaging family caregivers and health system partners in exploring how multi-level contexts in primary care practices affect case management functions and outcomes of patients and family caregivers at end of life: a realist synthesis. *BMC Palliat Care*. 2021;20(114):1–30. <https://doi.org/10.1186/s12904-021-00871-8>.
 29. Cashin Z, Daley S, Hebditch M, Hughes L, Banerjee S. Involving people with dementia and their carers in dementia education for undergraduate healthcare professionals: a qualitative study of motivation to participate and experience. *Int Psychogeriatr*. 2019;31(6):869–76. <https://doi.org/10.1017/S1041610218001357>.
 30. O’Keeffe S, Weitkamp K, Issacs D, Target M, Eatough V, Midgley N. Parents’ understanding and motivation to take part in a randomized controlled trial in the field of adolescent mental health: a qualitative study. *Trials*. 2020;21(952):1–13. <https://doi.org/10.1186/s13063-020-04857-3>.
 31. Brazil K, Kaasalainen S, McAiney C, Brink P, Kelly ML. Knowledge and perceived competence among nurses caring for the dying in long-term care homes. *Int J Palliat Nurs*. 2012;18(2):77–83. <https://doi.org/10.12968/ijpn.2012.18.2.77>.
 32. Chen IH, Lin KY, Hu SH, Chuang YH, Long CO, Chang CC, Liu MF. Palliative care for advanced dementia: knowledge and attitudes of long-term care staff. *J Clin Nurs*. 2018;3–4:848–58. <https://doi.org/10.1111/jocn.14132>.
 33. Luckett T, Luscombe G, Phillips J, Beattie E, Chenoweth L, Davidson PM, Goodall S, Pond D, Mitchell G, Agar M. (2021). Australian long-term care personnel’s knowledge and attitudes regarding palliative care for people with advanced dementia. *Dementia*. 2021; 20(2):427–443. <https://doi.org/10.1177/1471301219886768>
 34. Bolt SR, van der Steen JT, Schols JM, Zwakhalen SM, Pieters S, Meijers JM. Nursing staffing needs in providing palliative care for people with dementia at home or in long-term care facilities: a scoping review. *Int J Nurs Stud*. 2019;96:143–52. <https://doi.org/10.1016/j.ijnurstu.2018.12.011>.
 35. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14(89):1–9. <https://doi.org/10.1186/1472-6963-14-89>.
 36. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014;41(5):545–7. <https://doi.org/10.1188/14.ONF.545-54>.

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