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Abstract

A novel registered practical nurse-led video conferencing approach using PIECES™ for team-based care planning was developed to engage family/care partners in the care of older adults. The objectives were to: (a) explore the experiences of older adults and family/care partners in collaborating in implementation science research in long-term care (LTC); (b) identify facilitators and barriers to engaging older adults and family/care partners in implementation science research; and (c) share recommendations to support the engagement of older adults and family/care partners in research. A qualitative descriptive design was used. Two older adults and two family/care partners from two Canadian LTC homes were involved in the research. Data, comprised of interviews with older adults and family/care partners, and notes from research team meetings, were analyzed using thematic analysis. Older adults and family/care partners perceived they made valuable contributions to the research project. They expressed beliefs that care delivery required improvements for older adults with responsive behaviours in LTC, which served as motivation to participate in the research project. Facilitating factors included the support of familiar LTC staff for older adults to engage in research activities and understanding the value of PIECES. A barrier to engagement for older adults was research terminology and processes described during team meetings. This research highlighted taken-for-granted factors in a collaborative research endeavour with older adults and family/care partners. One-on-one interaction, follow-up 'reporting' and presence of familiar LTC staff are needed to support meaningful engagement of older adults and family/care partners in research.

Keywords

Patient- and family-centred care, patient engagement, research partner, long-term care, older adult, family, care partner, qualitative

Introduction

In many countries the COVID-19 pandemic had a detrimental impact on older adults living in long-term care (LTC) homes (i.e., settings that provide 24-hour nursing care) resulting in high mortality and significant decline in their physical, cognitive, and mental health.^{1,2} Strict infection control protocols to contain the spread of the COVID-19 virus, including restricting family visits and eliminating social gatherings such as communal dining and

group recreational programs, contributed to higher incidences of responsive behaviours in older adults in LTC.^{3,4} Responsive behaviours (e.g., yelling, restlessness, hitting) are expressed by half of the population of older adults with dementia in LTC as a way to communicate unmet needs such as boredom, fear, pain, thirst, and hunger.⁵ When left unaddressed, these behaviours can lead to an increased staff and family/care partner burden and diminished quality of life for these older adults.⁶ Also, longstanding challenges in LTC – for instance, inadequate

human and financial resources, inadequate staff education and skills development, and poor leadership support – may have contributed to an exacerbation of responsive behaviours during the pandemic.⁷

In Canada, the need to prioritize engaging family/care partners in high-quality care for older adults in LTC homes was recognized as one of *six promising practices* (i.e., presence of family) by the Canadian Foundation for Healthcare Improvement (CFHI)⁸ to mitigate the impacts of future COVID-19 outbreaks in LTC homes. This research team worked with Registered Practical Nurses (RPNs), as the largest regulated workforce in Ontario LTC homes, to integrate family/care partners into care planning. During the pandemic, families were left out of research as some researchers perceived that their engagement would cause delays in making important decisions.⁹ Moreover, little has been written about how to best involve older adults and families in LTC research. Older adults living in LTC are often assumed to be vulnerable and incapable due to physical and cognitive disabilities.¹⁰ As Cranley et al. (2020) suggested, research should not preclude LTC residents; a number of innovative approaches can be applied for meaningful engagement of older adults in research.¹¹ Including older adults provides much needed guidance for developing and adopting best practices in LTC. An implementation science lens was adopted by this research team to embed stakeholders, including older adults, from the project onset.¹¹

Implementation science often involves key stakeholders and end users in developing interventions and improving processes for care delivery.¹² The objective of implementation science is to reveal challenges and enablers of intervention uptake across multiple important groups and develop strategies to promote the success of an intervention.¹² Active engagement of a multidisciplinary team of university-based researchers and operational partners (e.g., older adults, families, RPNs and other providers, administrators) within the actual intervention setting are key ingredients for positive outcomes and changes.^{12,13} Further, implementation science consists of purposeful engagement of individuals with lived experience including older adult residents and family/care partners in roles that extend beyond traditional forms of research participation.^{14,15}

In the last ten years there has been a fast-growing interest in the meaningful engagement of patients or persons with lived experience in research.^{14,16} For example, persons with lived experience provide a perspective that university-based researchers do not have.¹⁷ Meaningful engagement of persons with lived experience can lead to improved research questions that hold greater relevancy and enhanced alignment between research and the needs of end-users.^{14,18-20} The engagement of older adults and

family/care partners in research facilitates knowledge transfer and promotes transparency and accountability to gain the trust of public citizens.^{17,21} Challenges related to engaging persons with lived experience in research need to be thoughtfully addressed to increase our capacity to find, recruit and engage such individuals in the research process.^{14,18,22}

In response to the growing increase of responsive behaviours among older adults in LTC related to changes brought on by the pandemic, we determined that there was a need to explore use of a care planning intervention called PIECES™.²³ PIECES is an acronym used in client/patient assessment: Physical, Intellectual, and Emotional health, maximizing the Capabilities of an individual to support quality of life, integrating the living Environment of a person, and encompassing a person's Social circumstances including beliefs, culture, and life story.²³ The holistic framework of PIECES supports family/care partner involvement with the interdisciplinary health care team to assess the physical and mental health (e.g., cognitive, emotional, social, psychological) needs of older adults.²³ Within the PIECES model, family/care partners are key participants. Our research team identified the need to engage older adult residents of LTC homes and family/care partners through implementation science methods to better inform the PIECES research and care delivery within LTC.

Purpose

Despite the growing literature on meaningful engagement of persons with lived experience in research, there are few studies involving older adults and family/care partners in LTC research - a gap even more pronounced within dementia care.^{17,24,25} The objectives of this study were to: (a) explore the experiences of older adults and family/care partners in collaborating in implementation science research to improve care for older adults in LTC during COVID-19 and beyond; (b) identify facilitators and barriers to engaging older adults and family/care partners in implementation science research; and (c) share recommendations of older adults and family/care partners to support the engagement of research partners in implementation science research in LTC.

Methods

PIECES Implementation

The COVID-19 pandemic led to an increase in uptake of virtual technology to support healthcare delivery.²⁶ In accord with the increase of virtual technology use, this study employed a novel virtual adaptation of PIECES training using PHIPA (Personal Health Information Protection Act)-approved ZOOM. Synchronous virtual family care conferences were led by RPNs champions in the LTC homes. RPNs are nurses who complete two-year

college-level programs, licensed by the College of Nurses of Ontario, and practice autonomously within their scope as well as collaborate with others.²⁷ RPNs led care conferences that included family/care partners who were off-site, the older adult, and other health care team members (on- or off-site) to create an integrated care plan. This virtual PIECES intervention provided the health care team with care protocols to maintain quality in care practices during COVID-19 pandemic and inclusion of family in care decisions.

Study Design and Setting

A qualitative descriptive design was employed in this study which allows for straight, yet detailed descriptions and interpretations of data while remaining close to the words of participants.²⁸ The research occurred in two LTC homes in Ontario, Canada. These LTC homes are both considered of moderate size and have been operating for greater than 30 years. One LTC home operates as a for-profit venture and has 136 beds located in basic, semi-private and private rooms. The second LTC home operates as non-profit and has 146 beds located in private rooms and two to three-bed ward rooms. With regards to staffing in both homes, there is a registered nurse (i.e., bachelor's degree-level nurse) and RPN and RPN on duty 24 hours a day, 7 days a week as well as personal support workers. Both LTC homes offer resident care services, such as medical and nursing care, nutrition, housekeeping, recreational programs, as well as additional services including physiotherapy and social worker services.

Sample and Recruitment

We used convenience sampling to recruit potential suitable older adults and family/care partners study participants.²⁹ Managers were asked by the research team to email or approach potential individuals in person within the LTC home to determine whether they would be interested in participating as research partners. Two older adults and two family/care partners were sought to participate in this study. To be eligible to participate older adults needed to have been a resident of one of the two LTC homes and family/care partners had to have a loved one living as a resident in one of the two LTC homes. All research partners had to be able to speak and understand conversational English. A small number of research partners was sought as it was perceived that each partner would have multiple opportunities to fully contribute to the study. This helped to gain an in-depth understanding of the older adults and care partners experience with PIECES and the research process See Figure 1 for an overview of the meaningful activities of research partners for the first year of the study.

Data Collection

Older adults and family/care partners each participated in one semi-structured individual interview (total of four interviews) that explored their interest in being research

partners and their experiences with the virtual PIECES research project. These interviews were conducted by two members of the research team with qualitative training [MH, MY] via Zoom video conferencing. We asked: (a) what were your thoughts when you were initially approached about being part of this research; (b) how do you feel you've been included so far in the research; (c) in your role, what influence do you think you have had to date; and (d) what would you like to see about the involvement of older adults/family going forward? Interviews were 30-60 minutes. In addition, older adults and family/care partners each attended research meetings that were all held virtually, which were intended to bring together all stakeholders to problem-solve and develop research processes that were relevant and realistic for LTC. These meetings were held biweekly to discuss successes, barriers, and adaptations to the implementation process. Family/care partners also provided written comments about their experiences with the virtual PIECES research by completing a patient engagement survey that included open-ended questions (i.e., the Public and Patient Engagement Evaluation Tool).³⁰ Meetings and interviews were recorded and transcribed verbatim by an experienced transcriptionist for analysis with the informed consent of research partners. Field notes were documented by MH and MY throughout meetings and interviews.

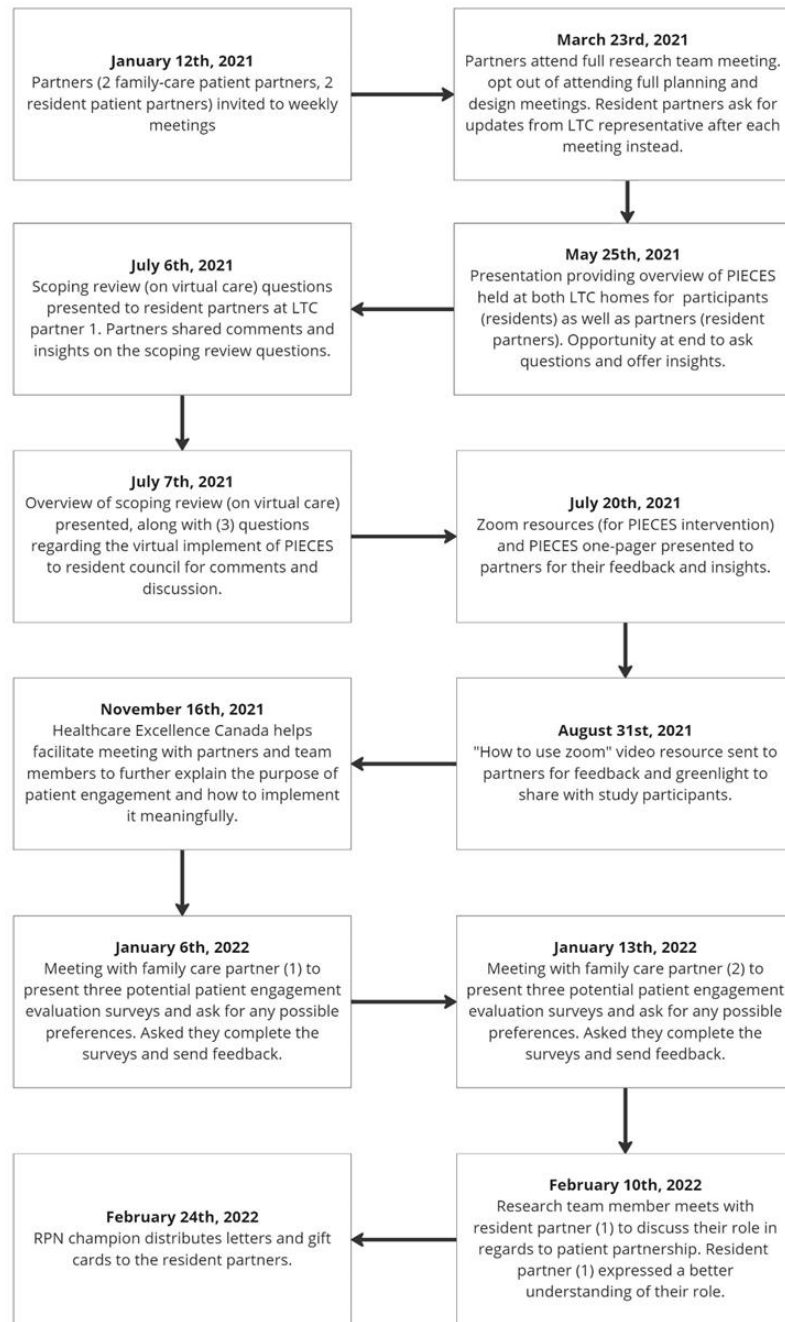
Data Analysis

Themes were constructed using Braun and Clarke's thematic analysis framework³¹ which was selected to ensure that the development of themes was directly informed by the perspectives of older adults and family/care partners. The six phases of thematic analysis include: (a) becoming familiar with the data; (b) coding; (c) developing themes; (d) reviewing themes; (e) constructing a definition for themes and labelling them; and (f) creating a report.³¹ MH and MY both reviewed transcripts twice before performing coding. Initial themes were developed and then reviewed by the entire research team for decisions surrounding inclusion, renaming, or excluding themes. A report was generated to summarize themes.

Rigour and Trustworthiness

Numerous approaches were employed to enhance rigour and trustworthiness in qualitative research including addressing Lincoln and Guba's (1985) criteria: credibility, transferability, dependability, and confirmability.³² Credibility of the findings was ensured through the use of triangulation between the research team members experiences engaging with the study participants and the findings from the qualitative interviews. This strategy also complemented and supported data validation.³² Detailed descriptions of the setting and sample of participants were used to ensure that findings were transferable to other research contexts.³² The research team ensured that study processes were logical by conducting a comprehensive

Figure 1. Overview of research activities completed with research partners



review of the existing literature to determine gaps in the literature.

Ethical Considerations

Ethics approval was received from the local University Ethics Boards (#118629 and #H21-01428). Study IDs were assigned to research partners to maintain anonymity and participation was voluntary. All research partners

provided either written informed consent, indicated by signing a consent form, or verbal consent which was audio-recorded. It was determined that research partners were providing sensitive information about their experiences and should therefore consent to participating. Prior to participating in the research, all potential partners received a letter of information and had opportunities to ask questions before providing informed consent.

Resources and study updates were provided to participating partners at regular intervals to support their engagement. The three core principles - respect for persons, concerns for welfare, and justice - of the Tri-Council Policy Statement were upheld throughout the study.³³ Family engagement activities and gift cards were provided to all older adult residents and family/care partners as a gesture of appreciation.

Results

Demographic Results

Older adults and family/care partners who took on the role of research partners in the study were all aged 55 years and older. One of the partners identified as female. There were equal numbers of older adults and family/care partners. See Table 1 for demographic characteristics of research partners.

Overview of Themes

Themes were categorized under: (a) experiences of older adults and family/care partners in engaging in implementation science research, (b) facilitators and barriers for engagement of research partners in implementation science research, and (c) recommendations for meaningful engagement of partners. To protect the identity of research partners study numeric IDs are provided along with direct quotes. OA is used to describe older adult research partners. FCP is used to describe family/care partner who are in the role of research partners.

Experiences of Older Adults and Family/Care Partners in Research

Felt Contributions Were Made to the Research

Older adults and family/care partners perceived that they were able to meaningfully contribute to research on implementing PIECES. They recalled their engagement in

numerous activities related to the research process including reviewing Zoom instructions created to assist family/care partners in virtual meetings, providing feedback on scoping review findings addressing what is known about virtual team-based care for older adults in LTC, and sharing experiences with implementation science research through a videorecording for a LTC conference. One research partner described how their ideas were received by the research team: “...when you were talking about setting up Zoom and you had all these instructions and all that stuff, just tone it down and help people understand it...you actually listened to us” (OA2). Research partners perceived that they were involved in improving care processes for older adults in LTC, stated as “Finding the best and easiest way for residents and staff to communicate with family” (FCP1). A family/care partner reported that “Zoom meetings enabled all participants to feel a part of the process” (FCP2). With the permission of older adults and family/care partners, the research team ensured that research partners were publicly acknowledged for their contributions in reports, manuscripts, and presentations. One older adult research partner was very proud of being named in contributions:

I’m on the internet apparently. I was told that I’m on the internet. I don’t know if it’s gathered much wind yet but that’s what they tell me. I’m starting to achieve what I’ve wanted to do for so long because when I was younger, I had a very tough childhood. (OA1)

Diverse Perspectives Shared Within the Team

The research team was comprised of various stakeholders and members including older adults, family/care partners, university-based researchers, undergraduate and graduate research trainees, RPN LTC frontline staff, LTC administrators, and organizational representatives (i.e., WeRPN, PIECES Canada). Older adults and family/care partners appreciated that diverse perspectives were used to inform the PIECES research. One older adult research partner perceived that including a wide range of views in research allows “a good balance of beliefs and such” (OA2). Similarly, one family/care partner shared the importance

Table 1. Demographic characteristics of research partners (N=4)

Variable	n (%)
Age	
• 55 years of age and older	4 (100%)
Sex	
• Female	1 (25%)
• Male	3 (75%)
Research partner(s) in the study from LTC home Site 1	
• Older adult resident	2 (50%)
Research partner(s) in the study from LTC home Site 2	
• Family/care partner	2 (50%)
Previous experience in research	
• No	4 (100%)

of including the voices of older adult residents and families of LTC homes in research: *“I think it is paramount that a family representative is involved in the research going forward. The ability to garner or get the perspective of a family or family members even residents. That is the collaboration that benefits everyone”* (FCP2). All members of the research team had a role in shaping the implementation of PIECES in LTC to ensure that the intervention met the needs of older adults and families.

Lack of Clarity of Research Partner Role in the Beginning

At the start of the implementation science research, older adults and family/care partners lacked a solid understanding of what their role as a research partner entailed. *“At the beginning I didn’t realize that I was going to be a representative for all families”* (FCP2). In attending initial research team meetings older adult research partners perceived that the research was more relevant to nurses supporting residents in LTC and did not understand how they could contribute. One older adult described: *“At the beginning it was really over my head because I didn’t realize that it was all about nursing but once it got explained to me exactly what it was, then I understood a little more what was going on”* (OA1). Another older adult similarly shared that they had a better understanding that the study went beyond nursing practice: *“...they were talking about bringing nurses into the field. There’s so much more than that”* (OA2). Furthermore, there was a perceived need for researchers to be clear about the input sought from research partners early on in implementation science research:

I think they [research partners] really have to understand what’s going on and what it’s about and what your input would probably be on certain issues...and a lot of it is going to go over their head, they’re going to get discouraged. I mean I could tell you the first couple of weeks I thought why am I here? So I just think to keep it simple so they understand what this research is about and really specify what you want from that person, whether or not they can give you that input. (OA1)

Greater Research Engagement with One-on-One Meetings

At the start of the research, older adults and family/care partners attended some initial meetings with the larger research team. They reported feeling that these were difficult to follow, required significant commitment, and may not have much relevance for their role in the research. Having separate meetings with research partners, especially older adult research partners, were found to provide them with better opportunities to both engage in the research process and share their ideas. When asked if he felt included in the research, one older adult reported, *“In the beginning not so much but now, this is much better. There aren’t six faces up there”* (OA1). Research partners reported feeling that their contributions were valued through one-on-one meetings: *“...the smaller group really is what makes me say that. I*

can go one on one with you, that’s much better in my eyes than trying to do six people” (OA1). Another older adult similarly noted that their ideas and responses were better captured by the research team through individual meetings: *“Sometimes it’s better one on one because not everybody is listening at the same time as you’re talking [in a group]”* (OA2).

Facilitators and Barriers for Meaningful Engagement in Research

Support From Staff at the LTC Home Enabled Participation of Older Adults

Older adult research partners perceived that they were meaningfully engaged in implementation science research because of the support they received from staff at their LTC home. LTC staff were present during individual meetings with older adults to assist them in using Zoom technology for meetings and helped to clarify questions. *“If I have somebody with me, like this lady here [LTC staff], yeah, I feel confident [to participate]”* (OA1). LTC managers who approached older adults to be research partners provided helpful explanations about their role and helped them to see the value of their involvement. *“[LTC manager] explained after a few meetings what it [the study] was about and we went on from there...She explained pretty well what it was all about, you know, what PIECES was all about so yeah, pretty well I’m in”* (OA2).

Understanding the Value of the PIECES Intervention Supported Engagement

A facilitator for older adults and family/care partners in engaging in implementation science research was having a good understanding of the value of the PIECES intervention for residents experiencing responsive behaviours. The research partners wanted to be involved in the study to improve care for residents in LTC homes. Family care/partners perceived that a benefit of PIECES was its gathering of *“Input and discussions from all those [LTC staff] that deal with our loved ones”* (FCP1). Another family/care partner similarly reported that the value of PIECES was the *“Team based focus and ability to have input on how staff or LTC professionals interact with families”* (FCP2). Older adults and family/care partners had various motivating factors to engage in the research. For instance, one family/care partner shared:

Having recently moved my mom into LTC, the ability to improve the quality of interaction with staff there was one of my main motivating factors. The holistic approach to every facet to her wellbeing was really one of my main reasons, a sense of service, anything I could do to help me in that process is going to be a benefit to us all. (FCP2)

Older adult research partners reported feeling motivated to participate in the research because they saw a need to support and improve the care of their fellow residents. One of the older adult research partners could relate to the need to support quality of life in residents when addressing

mental health issues. “Well right away I wanted to do it...I don’t like to see people suffer, especially with mental illness like I have” (OA2). Another older adult research partner perceived the need to support the LTC home they lived in, and the care that staff provides for residents. “I just wanted to be involved, if it helped the home...Would it help other people here? If it could help somebody and not necessarily going to help me but if it helps somebody else, I’m all for it (OA1).

Use of Research Terminology During Team Meetings was a Barrier

Older adult research partners perceived that they had a difficult time following conversations when research terminology and processes were discussed during team meetings. This was especially made challenging when too many individuals were present at meetings. An older adult research partner expressed:

I think the biggest thing is when there’s four, five or six of you together and everybody’s talking about something different...and a lot of it does go over your head, really it does because we’re not in that field, you know, we’re just innocent bystanders if you want to call us...it’s just that sometimes the explanation of whatever you’re talking about could be a bit simplified and, you now, make it real easy to understand. (OA1)

Recommendations for Meaningful Engagement of Research Partners

Regular Feedback and Sharing of Research Progress

Research partners recommended that the research team provide regular feedback on whether and how their ideas were used to improve the implementation process. An older adult research partner shared:

It basically all boils down to the same thing, that you commit to the meetings and then you leave and then that’s it..It would be more beneficial to get more feedback from what’s happened because of the meeting if anything. That’s all you need is a little bit of feedback (OA1).

The same research partner suggested sending an email from time to time to communicate about outcomes:

Even just like a simple email to say that, on this point in the meeting we’ve done this or we’re looking into this or we’ve changed that...it’s just to keep you informed with what’s going on and you know we’ll discuss more at the next meeting (OA1).

Older adult research partners also perceived that it would be helpful to better inform them about the purposes of meetings so that they know what to expect. Family/care partners similarly shared the need to connect with research partners regarding study findings. “It would be nice to have a wrap up Zoom meeting to report the findings from your study” (FCP1).

Increasing the Number of Research Partners Involved

The voices and perspectives of older adults and family/care partners were perceived by the research partners as very important in implementation science research. In light of this, research partners recommended increasing the number of older adults and family/care partners involved in such studies aimed at improving care delivery in LTC. One family/care partner shared the need to have greater involvement of families using virtual technology:

I think one of the recommendations would be...possibly even more interaction? I am the lone representative with my mom, could that be expanded? Doing things virtually, even having a little more input, the ability to meet the team virtually is huge. A phone call doesn’t always serve its purposes. But being able to see the nuances and the non-verbal aspects [using video] is invaluable. (FCP2)

An older adult research partner similarly shared the need to engage more residents from different LTC homes in research.

I think you’ve got a lot of people from different areas involved with it. I think there could be a little more, maybe a few more residents or...from other places even to see what their comments or thoughts are...Because let’s face it...It’s not about the nurses, it’s about the residents. (OA1)

Discussion

This study highlighted that older adults and family/care partners found it meaningful to participate in research affecting their LTC communities. This study extended literature on implementation science particularly within the older adult/LTC context. Older adults and family/care partners within LTC have the potential for meaningful contribution to research. In addition, the subsequent implementation of their suggestions, as well having the support of LTC staff on hand for older adults, helps to facilitate their engagement and improve the overall quality of research in this domain.

As previously noted in the literature, stakeholders who are affected by the implementation of research are likely to provide valuable insights, improving research relevance and usability.^{14,18-20,34,35} Aside from the practical implications, patient engagement also reminds researchers of the purpose behind their work – to improve standards of living.¹⁴ Importantly, older adults and family/care partners also found the opportunity to provide insights and feedback on process of implementing virtual PIECES as an impactful experience for them. In the implementation of PIECES, older adults and family/care partners saw their role as research partners as a chance to help others in similar situations as themselves. This opportunity highlighted their desire to alleviate potential suffering within members of their community.

However, although stakeholders may find meaning in their role, they should not be overburdened with the expectation of being the sole representative of all partner voices. Furthermore, as mentioned by a family/care partner, expanding the number of partners would help to also improve the representativeness of lived experiences of older adults and their care partners in LTC contexts. Understandably, involving individuals in research is a sometimes daunting task, as it may appear as time-consuming and difficult by the research partner.¹⁸ Consequently, stakeholders who have participated in research studies before and are familiar with the process are sometimes oversampled by other research projects, resulting in a “professionalized” sample that may no longer be representative of the true stakeholder population.¹⁴

Breaking the barrier separating persons with lived experiences from research can be accomplished via the integration of facilitators. Facilitators can help explain research jargon and terms likely to be unfamiliar to stakeholders, as well as interjecting to provide partners an opportunity to contribute during larger group meetings.³⁶ Furthermore, staff support can play a key role in easing the process of patient engagement through their familiarity with both partners and administrative systems that are unfamiliar to researchers. As highlighted in previous studies, engaging persons with lived experiences as partners requires support from staff who are knowledgeable in both the communication and administrative aspects of meeting facilitation.¹⁴ Similarly, research partners felt “*confident [to participate]*” (OA1) with the support of LTC staff during engagement events. Ultimately, the implementation of facilitators, alongside collaboration with staff, can provide a comfortable environment for partners to share their thoughts.

Importantly, it is just as critical to provide a space to share thoughts as it is to genuinely hear them. Avoiding purely symbolic engagement related to unequal power relations, also known as “tokenism”, allows research partners to share genuinely, ultimately resulting in more relevant outcomes for patients.^{35,37} In our study, research partners expressed appreciation that their ideas were both enacted upon and acknowledged in publications and presentations. Neglecting to take the input of research partners genuinely negates the purpose of patient engagement; which builds on the concept that individuals with lived experiences know what is needed to improve care.^{34,37} The result of ignoring their voices is a potential waste of resources and funding, as research outcomes lacking their perspectives may then lack applicability within practical settings.³⁷

With regards to implications for practice and policy, there is a need to improve the quality of care for residents and families by collaborating with older adult residents with lived experiences and partnering with LTC homes to

ensure applicable research outputs. A recommended actionable arising from this and similar research would be to ensure that policies informing intervention research stipulate that research stakeholders should include older adults and family/care partners and provide them with the opportunity to meaningfully participate in the planning and implementation of interventions. Study findings also have implications for research as more meaningful results and potentially positive outcomes are found when partners collaborate with researchers.^{18,20,22} Two such positive outcomes are increased patient enrollment and retention rates.¹⁸ To increase the number of individuals involved as research partners there is a need to clearly indicate the purpose of co-design and participation and clear any misperceptions about research. Future research in LTC should comprehensively report on the specific research activities that research partners complete and the impact that these had on the quality of research.³⁸

Strengths and Limitations

The use of a qualitative study design allowed research partners to share, in their own words, their experiences living in LTC homes or being family/care partners. Our sample of research partners was however limited in size (n =4) and demographics, such as race and ethnicity. The challenge of restricted visitations also made it difficult for the research team to build relationships with research partners. Future research involving research partners would benefit from a larger and more racially and ethnically diverse sample.

Conclusion

Engaging persons with lived experiences as partners is an active process that requires collaboration between researchers and partners, as well as support from staff who can act as facilitators during engagement events. In order to ensure meaningful engagement, stakeholder input should be considered and implemented, where applicable across all stages of research. Support and resources (e.g., explanation of research terminology and process in lay language) should be put in place to ensure that stakeholders are contributing at the best of their abilities.

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