Canadian Journal on Aging / La Revue canadienne du vieillissement

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Raise Your Voice: How to Increase the Effectiveness of Resident and Family Councils in Long-Term Care Homes

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Article

Cite this article: Staempfli, S., Havaei, F., Dawson, L., Novek, S., Slater, K., Kaulius, M., & Ahmed, A. (2025). Raise Your Voice: How to Increase the Effectiveness of Resident and Family Councils in Long-Term Care Homes. *Canadian Journal on Aging / La Revue canadienne du vieillissement*
https://doi.org/10.1017/S0714980825000029

Received: 03 May 2024
Accepted: 09 January 2025

Keywords:
caregiving; health policy; integrated knowledge translation; nursing homes; participatory research; patient partner integration

Mots clé:
connaissances intégrées; recherche participative; règlement en santé; partenariat avec les patients; proche aidant; soignant; centre de soins longue durée

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Abstract

The devastating impacts of the COVID-19 pandemic highlighted the missing voices of families and residents in long-term care (LTC) decision-making and policy processes. Family and resident councils constitute one method of raising these voices, but there is currently a gap in evidence of how to promote the effectiveness of these councils. We conducted five focus groups and two interviews with LTC home leaders, residents, family members, and advocates in British Columbia using a participatory approach integrating knowledge-users throughout the research process. Using a framework analysis, we found modifiable (communication, structure, recruitment/engagement, council leadership, culture/attitudes, and resources/supports) and non-modifiable factors (medical complexity of residents and short lengths of stay) affecting council effectiveness. We discuss strategies implemented by knowledge-users to address modifiable effectiveness factors and construct a preliminary tool (a 35-question survey) that operationalizes and identifies areas that can increase council effectiveness in practice to ensure that their voices are heard in LTC decision making.

Résumé

L'impact dévastateur de la pandémie COVID-19 a mis en valeur l'absence d'écoute des voix des résidents et des familles lors du choix de politiques et les prises de décision en matière des centres d'hébergement de soins de longue durée (CHSLD), en Colombie-Britannique. Les conseils des résidents et des familles sont une méthode utilisée pour entendre la voix de ces derniers. Cependant, il y a un manque de preuve relié à la façon d'augmenter l'efficacité de ces conseils. Durant notre processus de recherche, nous avons mené cinq groupes de discussion et deux entretiens oraux avec les résidents des CHSLD, les membres des familles, les représentants et les dirigeants des CHSLD en utilisant une approche participative en intégrant des utilisateurs des connaissances. Notre analyse du cadre démontre deux types de facteurs ayant un impact sur l'efficacité des conseils: les facteurs modifiables (la communication, la structure, le recrutement/l'engagement, la direction du conseil, l'attitude/la culture, le support/les ressources) et les facteurs non modifiable (la complexité médicale des résidents et la courte durée de séjour). Nous discutons de stratégies utilisées par les utilisateurs des connaissances afin de traiter des facteurs modifiables et nous avons construit un outil préliminaire, un questionnaire de 35 questions, qui rend opérationnelles et identifie les éléments permettant d'augmenter l'efficacité des conseils de résidents et des familles pour s'assurer que leur voix soit entendue lors de la prise de décision en matière des CHSLD, en Colombie-Britannique.

Introduction

Long-term care (LTC) home legislation in many jurisdictions in Canada (e.g., British Columbia, Alberta, Ontario, and Nova Scotia; Keefe et al., 2024) requires LTC homes to provide residents, family, and friend care partners with the opportunity to participate in forums where residents and their family and friend care partners get together on a regular basis and voice their opinions regarding the direction, priorities, and day-to-day operations of the LTC home (Gagnon et al., 2017). In LTC homes, resident, family, and friend care partner voices are increasingly heard via resident and/or family councils. While there is no agreed upon definition of resident and/or family councils, these forums broadly refer to groups of residents

and/or family members who meet on a regular basis for the purpose of maintaining and improving the quality of life of those living in LTC homes (Baumbusch et al., 2022; British Columbia Ministry of Health, 2023). Council structures vary, with resident councils composed of people who live in LTC homes, family councils composed of family members and friends of LTC home residents, and joint models that include both groups (Znidarsich et al., 2016). Descriptions of the purpose of councils also vary in the literature, and may include: providing information and peer support (Baumbusch et al., 2022; Curry et al., 2007); promoting collaboration and communication among leadership, families, and residents (Baumbusch et al., 2022); facilitating resident and family input into decision making (Baumbusch et al., 2022; Znidarsich et al., 2016); and promoting residents' rights and collective action (Baumbusch et al., 2022; Gagnon et al., 2017).

Although versions of resident and family forums have been in practice internationally for decades, research on the factors that enable councils to achieve the above-stated goals remains limited. The available international research points to several possible factors that may impact the operation and influence of resident and family councils, such as the availability of administrative support (Curry et al., 2007); communication between the council and management (Gagnon et al., 2017); access to training and support in group facilitation (O'Dwyer & Timonen, 2010); facility resources and constraints (O'Dwyer & Timonen, 2010); and the level of independence of the council (Gagnon et al., 2017; O'Dwyer & Timonen, 2010). These findings provide important insights into the factors that can impact the effective operation of resident and family councils; however, the evidence base remains scant, is not current, and does not focus on the Canadian context.

The start of the COVID-19 pandemic highlighted long-standing inequities and care quality challenges that have burdened the Canadian LTC sector for decades (Estabrooks et al., 2020; Havaei et al., 2022). During the first six months of the pandemic, nearly 70% of COVID-19-related deaths in Canada occurred in LTC homes, and resident deaths from all causes increased during the first year of the COVID-19 pandemic (Canadian Institute for Health Information, 2021). In response to the proliferation of COVID-19 in LTC homes, the Public Health Agency of Canada mandated several pandemic management strategies to curb the spread of the COVID-19 virus to protect the health and safety of the LTC community (Liu et al., 2020). Although evidence indicates that these pandemic management strategies reduced the spread of the virus (Ernst & Young, 2020), these policies resulted in unintended impacts to the health and well-being of the same LTC community (Ernst & Young, 2020; Havaei et al., 2022; Staempfli et al., 2022). Researchers and advocates have argued that including the perspectives of LTC home families and residents (which were largely absent from the pandemic policy-making process) could have led to more equitable pandemic- and public health-related policies and strategies (Havaei et al., 2022; Keefe et al., 2024; Staempfli et al., 2022; Tupper et al., 2020).

In November 2022, British Columbia implemented new LTC regulations to strengthen the position of resident and family councils in LTC homes (British Columbia Ministry of Health, 2022). Currently, there are 297 publicly subsidized LTC homes in British Columbia with 28,064 beds (Office of the Seniors Advocate, 2024). The new regulations require LTC operators to support the operation of resident and family councils and promote their independence, for example, by providing administrative support and meeting space, as well as meeting with the council on invitation, and providing written responses to council recommendations (British Columbia Ministry of Health, 2022).

Since the implementation of the new regulations, however, many British Columbia LTC communities are still facing challenges in establishing and running independent family and resident councils. There is a dearth of current knowledge regarding the factors that influence family and resident council's ability to function and enact change in LTC homes, potentially limiting the ability of LTC communities to put these new regulations into practice. Our research addresses this gap by investigating what factors contribute to the effective functioning of family and resident councils, and provides suggestions for families, residents, advocates, and LTC staff and leaders to overcome barriers to ensure the voices of families and residents are heard and considered in LTC decision making across BC.

Methods

We conducted a qualitative study of resident and family council effectiveness in British Columbia, Canada using a participatory approach. This project received ethics approval from the University of British Columbia ethics review board (H23-02410).

Participatory approach

On its own, health research rarely leads to widespread change in practice (Canadian Institutes of Health Research, 2012). One evidence-based method of addressing the gap between academic knowledge and practice-based change involves including knowledge-users throughout the research process (Jagosh et al., 2012). A knowledge-user is someone who plays a role in the healthcare system and is likely to use research findings to make informed decisions (Canadian Institutes of Health Research, 2012). Integrating insights from knowledge-users is essential for producing practical outputs, minimizing the unanticipated barriers of implementing research results, and increasing research uptake in practice (Canadian Institutes of Health Research, 2012).

In Canada, the integration of knowledge-users throughout the research process is known as integrated knowledge translation (Parry et al., 2015). Realizing this process requires the development of partnerships between researchers and knowledge-users who collaborate throughout each stage of research: developing the research questions, collecting, analysing, and interpreting data, developing conclusions, and disseminating results (Parry et al., 2015). Both parties are understood as experts who contribute complementary knowledge and skills to the research process (Graham et al., 2018).

Our research team included two knowledge-user experts with extensive lived experience with respect to LTC councils. L.D. (research team patient partner, family council chair, executive member of the Vancouver Coastal Association of Family Councils and Independent Long-term Care Councils Association of BC) was involved in the initial funding proposal application submission; research question development; bi-monthly research team meetings; methodology development; participant recruitment; data analysis (including coding); interpretation of results; recommendation development; construction of dissemination materials (including journal publications and a short film); and the dissemination of research results. K.S. (family council chair, founder of Vancouver Island Association of Family Councils, and Family Councils of BC, and family council advocate) was involved in

https://doi.org/10.1017/S0714980825000029 Published online by Cambridge University Press

recommendation development, construction of dissemination materials, and the dissemination of research results. Their combined knowledge and experience helped to shape every step of this study with the goal of producing practical recommendations that can be used to help families and residents improve the effectiveness of their LTC councils.

Recruitment and sampling

Stratified, purposeful sampling was used to select participants for this study to ensure that the study results reflect the perspectives of various knowledge-users engaged in LTC councils. Stratified purposeful sampling involves intentionally selecting study participants who are part of a pre-defined strata (or group) and is useful for capturing major variations in information-rich cases related to the phenomenon of interest (Palinkas et al., 2015). Five groups of knowledge-users were identified: residents and family members who participate in councils, LTC home leadership, policy makers, and older adult advocates (e.g., program directors, clinical specialists) who have experience establishing and interacting with councils. A list of potential participants was created based on a preliminary literature review and on the personal experiences of four members of the research team (SS, FH, LD, and SN). A recruitment email request was sent by LD to potential participants, who were asked to respond to the research team if they were interested in participating. Family members and residents were offered a $25 Visa gift card for their time. Three follow-up emails were sent (by LD) over one month to encourage participation.

Data collection

We conducted five virtual focus groups (65–90 min) with a total of 15 participants. Focus groups included members of the same knowledge user group in order to minimize power differentials and help participants feel comfortable sharing their opinions and insights (Hamilton & Finley, 2020). We also conducted two virtual individual interviews (30–60 min) with knowledge-users who wanted to participate in discussions but could not attend the focus group sessions. We were not able to recruit any policy makers for this study. Only one participant who was scheduled to take part in a focus group did not participate nor answer follow-up requests. Each participant sent an electronically signed informed consent form prior to the commencement of focus group discussions and interviews.

Semi-structured questions were developed by FH and SS (based on a preliminary literature review) and revised by the research team. Focus group and interview questions asked participants about the participant's role in council, what they consider to be an effective council, to give examples of a success and examples of challenges in council, what they feel could improve the effectiveness of councils, and to share a story when they felt council was able to impact the lives of residents and families in the LTC home. Focus groups and interviews were held on Zoom (a secure online video conferencing platform) between October and December 2023 and were audio recorded and stored on a password-protected device. The recordings were automatically transcribed by Zoom. SS led the interviews and four of the five focus group discussions, whereas FH took reflexive notes during both individual interviews and four of the five focus group discussions. FH led one focus group discussion. Participants were encouraged to contact either FH or SS with any follow-up thoughts, concerns, or insights after focus group discussions and interviews.

Data analysis

We conducted a phenomenologically informed framework analysis, which allows for comparison of data within and across cases (i.e., focus group discussions and individual interviews), and is well-suited to data sets that cover similar topics and key issues (i.e., allows for structured categorization) (Gale et al., 2013). Framework analysis is also recommended for multidisciplinary teams because it provides clear steps to follow, which can result in an overview of a data set that is structured, holistic, and descriptive (Gale et al., 2013). A combination of deductive and inductive thematic analysis was used to provide structure for the analysis while also leaving space for unexpected aspects of the participants' experiences.

We followed the seven stages of framework analysis outlined by Gale et al. (2013). Verbatim transcriptions were automatically generated by Zoom and proofread and de-identified by SS (*Stage 1).* The de-identified transcripts, as well as the interview and focus group discussion notes, were read through by SS, SN, LD, and FH (the core research team) to familiarize researchers with the transcript content (*Stage 2).* The coding framework was then discussed and formulated by SS, SN, and LD (and confirmed by FH), and a strategy was developed to accommodate team members' different levels of experience with data coding (i.e., LD had not participated in data coding previously). Consensus was reached to use Microsoft Word (for accessibility), and that each pre-defined code would be colour-coded (for visual ease) to facilitate comparison between coded transcripts for each research team member. To start coding (*Stage 3)*, two focus group transcripts were selected. To ensure trustworthiness of results (as per Nowell et al., 2017), researcher triangulation was used (i.e., one transcript was coded by SS and SN, and the second was coded by SS and LD). Both transcripts were read line by line and coded (using both a pre-determined coding framework and open coding to ensure important and unexpected aspects of data were not missed). The coding team then compared and contrasted the individual coding of the transcripts during a meeting to ensure that all participant perspectives were adequately captured in the previously agreed upon coding structure (*Stage 4).* Adjustments were made to the coding framework (with consensus from the core research team), and this revised coding framework was used by SS and LD to each code all remaining transcripts *(Stage 5).* Coded data were compiled into a matrix (by SS with input from LD), where data from each category were summarized and reduced (in Microsoft Word document separate from the coding documents) while retaining the original meaning of data and including illustrative and interesting quotations *(Stage 6).* Reflexive notes from interviews and focus groups were examined and integrated (where appropriate) into the matrix, which, as per Nowell et al. (2017), can increase trustworthiness of results by encouraging researchers to be self-critical of the research process. Additionally, retaining original quotations provides a clear audit trail from the original data to the final themes discussed, which increases credibility of research results (Nowell et al., 2017). Finally, the matrix was used as a basis to interpret the data *(Stage 7).* SS maintained a separate document where reflexive impressions, ideas, and early interpretations of data were recorded (again increasing trustworthiness of results as per Nowell et al., 2017), which were reviewed along with the matrix during multiple

https://doi.org/10.1017/S0714980825000029 Published online by Cambridge University Press

Table 1. Participant demographics

Knowledge-user participant group	Age (years)	N (%)	Gender	
			Female	Male
Resident council participants	73, 74	2 (12%)	1	1
Family council participants	62–81	7 (41%)	5	2
Advocates	78, n/a	3 (18%)	1	2
Leaders	56–72	5 (29%)	3	2
	Total	17 (100%)	10 (59%)	7 (41%)

meetings with the core research team. During these meetings, summaries and interpretations of the data were discussed, ensuring meaning was retained and all participant perspectives were included in the analysis, and gradually, connections and relationships between categories emerged.

Results

In total, 17 participants ranging in age from 56 to 81 years participated in our study (see Table 1 for details). Five LTC home leaders in executive and management positions participated in the study. Leaders had between 7 and 30+ years of experience in leadership positions in LTC, with varying levels of involvement in LTC councils (e.g., weekly/monthly engagements, working on reviving council post pandemic restrictions, or organizing council meetings due to lack of leadership). The seven family council participants who participated in focus groups were children or spouses of residents currently living in LTC or who had recently passed away. Participants in this group had varying degrees of participation in family councils, from chairing family councils and attending monthly council meetings, to attending only a handful of meetings in the last few years. Two residents participated in focus groups, one regularly participated in council meetings, and the other served as co-chaired of their council. There were also three advocates who participated in the study, including program directors and clinical specialists, who have had between 10 and 30 years of experience advocating for older adult rights in LTC.

Our results showed multiple factors influencing council effectiveness that were perceived by participants to be both non-modifiable (i.e., outside of their control to modify) and modifiable (i.e., within their control to modify). Non-modifiable factors include the medical complexity of resident populations and an increasingly short length of stay in LTC homes. We also identified six categories of modifiable factors of council effectiveness: communication, structure, recruitment/engagement, council leadership, culture/attitudes, and resources/supports.

Non-modifiable effectiveness factors

We identified two key factors that impact council effectiveness that were perceived by participants to be outside of their control to modify.

Residents' medical complexity

First, participants reported that residents in LTC homes are increasingly medically complex, and a large portion of residents lack the capacity to participate in council meetings and/or articulate their own perspectives. One resident stated 'getting the right people out to the [council] meetings, people who can speak and who can articulate concerns as well as positive things that they want to say is really important' *(Resident 2)*. Participants felt that recruiting residents who could contribute to meetings, however, is increasingly difficult. One leader supported this claim, commenting 'it is sometimes challenging [to get residents to attend council meetings], because a couple of our neighbourhoods are very unique specialized populations and the residents aren't able to particularly participate in conversation or decision making, so that's always a challenge' *(Leader 5)*. Another family member observed that the makeup of the resident population has changed dramatically over the past 10 years, which has affected not only the ability of a council to understand what is important to residents, but also the ability of councils to run:

> In 2013, a good number of the residents, maybe 50% plus, were cognizant, mobile, able to come to the dining room for meals on their own. There was a good number of residents who were quite competent [for] speaking for themselves and about any issues they had, [but] by 2022 that had changed dramatically. [Out of] 60 residents, maybe only three or four who were really mentally competent, and the rest were anywhere from very limited competence to none whatsoever. So they could have been in a [council] meeting and they would not have understood anything that was being said or discussed, nor could they have contributed or voiced any concerns. *(Family 2-2)*

Residents short length of LTC stay

Additionally, the average time that a resident spends in LTC can be very short, which affects involvement in councils and affects council succession planning. One family member acknowledged these challenges:

> One of our most difficult challenges with family councils is that we have such a small pool of people to draw from to build our councils. People come in, they might be in for a couple of years, they pass away just about the time that they're starting to learn. If they've joined a council, they're starting to learn about the LTC system and how to have more of an effective council. Their loved one passes away, and then we start with someone new. *(Family 2-1)*

One LTC leader argued that this high turnover is one of the reasons an effective family council has not been established in their LTC home. Even though the leader stated that they would welcome a family council in the LTC home, they had not been able to get one established that is run independently of the LTC home leadership.

> The other challenge that I have with family council [is sustainability]. … Since Covid, our length of stay is around 10 months. So when you think about the experience of a family and LTC, the first few months are trying to understand the system, maybe dealing with your own grief, your own guilt that you couldn't care for [the resident]. And you've got them in this place. And you're interacting with our care team, just to make sure the care is up to speed. … Your loved one is here for 10 or 11 months. First few [months] you're getting to know us. You might make it to a couple of [family council meetings]. Then sure you say 'Okay, I'll help on council' and then your loved one passes away, and then you don't want to come back. So we try and engage families in a multitude of other ways, because, we haven't had good luck with family council. I've been in this seat for 6 years now we've never had an effective family council. *(Leader 5)*

Although the above non-modifiable factors can provide barriers to effectiveness, our results indicated there exist six modifiable factors that can increase effectiveness of councils.

https://doi.org/10.1017/S0714980825000029 Published online by Cambridge University Press

Modifiable effectiveness factors

We identified six key factors that impact council effectiveness that were perceived by participants to be within their control to modify.

Communication

Council effectiveness was perceived to be heavily influenced by communication practices between councils and the LTC leadership, which were deemed most effective when ongoing, transparent, and closed-looped (i.e., when requests or concerns are provided with direct feedback regarding this request/concern).

Participants described the importance of frequently used and defined avenues for information sharing between staff, LTC leaders, family members, and residents. One advocate described the success they have had using social media platforms for communication:

> We've had such a great uptake of a closed Facebook group … an internal messaging board or internal way that family caregivers within that setting could communicate with each other [is] helpful to help build engagement and trust and understanding that we are looking for the common good of the long-term care [home], but also providing that individual one-to-one support that naturally occurs with peer support. *(Advocate 1-1)*

Leaders emphasized that ongoing communication is especially important for newly admitted residents and family members. Leaders must keep 'laying the foundation' of trust through ongoing communication to establish healthy relationships between leaders, residents, and family members participating in council. 'I think if you can really put the work in there [with communicating with new residents and families] … it can save a lot of trouble down the road.' *(Leader 4)*. LTC leaders also emphasized the importance of their role in creating a space for councils to communicate:

> I think what also helps [councils] become successful and help with successful relationships [with leadership] is having a communication platform where they can [share information]. We have a family council tab on the website where they can put information, exchange information, which is important for their own transparency and people who want to access that information. Over the years [we've] been able to establish very clear understanding about communication between the council's executive and the senior leadership of the organization, which helps with transparency and strengthening relationships. *(Leader 1)*

Participants also emphasized the importance of transparency:

> Sharing of information with family council [is vital]. Sharing above and beyond [existing] questions [family members] may have, being proactive in bringing up-to-date information [to family councils] about anything and everything that can impact the facility, whether it be what is your staffing recruitment going on, what equipment have you been buying, what's the Ministry of Health saying today, what's [the Health Authority] doing today? Just literally anything and everything that is relevant. Sharing that with them I think really builds a sense of their understanding of how LTC works, what our constraints might be, what our strengths might be. *(Leader 4)*

One advocate emphasized the importance of including positive feedback to LTC staff/leadership so communication was not exclusively negatively focused.

> I would always end [family council meetings] with a 'kudos' section. … We would have [for example] cards that we made, and we talked about a caregiver or a program that we wanted to celebrate in the facility and we formalize it and take it [to them personally] just [to] say 'Hey, thank you. We want you to know that we really appreciate what you're doing'. [This type of feedback] gets a lot more traction … in terms of building relationships, [as opposed to] 'Oh, God! Here they come again', kind of thing. *(Advocate 2-1)*

It was perceived to be important by participants that council and staff/leadership provide timely and appropriate feedback regarding any issues/concerns raised by the council or staff/leadership.

> If [councils are] bringing up with an issue or concern or some suggestion, then it's structured to say, okay, who's responsible for looking at this further? And let's give the general timeline and then report back on that outcome so that people realize that their voice is going to be heard or if it's outside the parameter of either the boundary of the council or the care home, then can it still go somewhere and something be fed back … people just need to have that feedback. *(Leader 2)*

One resident described the challenges to council effectiveness when feedback is not received, and when accountability is not defined: 'We do not get an adequate response out of management here. The complaint process is…ineffective, often ignored. If you complain to a nurse, you don't get any feedback ever. Nothing happens going to the manager. Sometimes you get some response, sometimes it's not suitable. Sometimes it's ignored for lengthy periods.' (*Resident 1).*

Participants indicated that transparent communication can also be fostered by inviting staff/leadership to attend council meetings:

> For quite a while we had no management coming to the [resident council meetings] at all. I asked about this and said I really wanted some management presence there to listen to what we have to say, not run the meetings, but listen. And finally, this last meeting we did get our manager, [they] called [in the] resident care coordinator to listen and she was very good. She did listen and she took away some good ideas. *(Resident 2)*

Council participants also indicated a willingness to learn about the perspectives and challenges faced by LTC leadership.

> If staff want to come, they need to be invited or ask to be invited. And so far it's fairly new, but we have invited several of the department heads to come and explain what their goals are, what they're dealing with, because we want to understand what they're dealing with to know how we can help support them. *(Family 1-5)*

One leader suggested that inviting senior leadership to attend council meetings encourages family members and residents to attend: 'Our medical director… comes once a year and just talks about goals of care. It seems those are the times when we get more [council members] joining in. … We also try and rotate our leadership team to be present and do a little bit of a presentation.' *(Leader 5)*

Structure

Participants identified the structure of councils and council meetings as a strong influence on council effectiveness. Well-structured council meetings, characterized by recording and distributing meeting minutes, following a term of reference and a code of conduct, having clearly defined council participant roles, and running council meetings independent of LTC leadership were perceived to be most effective.

The structure was seen by participants to be 'fundamental to a successful resident council' *(Resident 1)*, to a successful family

https://doi.org/10.1017/S0714980825000029 Published online by Cambridge University Press

council *(Family 1-2*), and for an effective council relationship with LTC leaders: 'The need for terms of reference is actually crucial because it really will then define and clarify the purpose of the council, what they can or cannot, should and should not do' *(Leader 1).* One resident described the process of going through past minutes and approving them at every resident council meeting: 'Having that structure keeps us going' *(Resident 1).* Another participant discussed the importance of how structure 'really helps family caregivers or families to understand how the [council] process works and provides lots of time for contributions, for dialogue and for input' (*Advocate 1-1).*

Additionally, participants felt that councils who followed a code of conduct and who had well-defined roles (e.g., council chair) were more effective at running meetings and were more positively viewed by the LTC community. To illustrate, one advocate described an example where a family member dominated the conversation during council meetings, but when a code of conduct was introduced, conflict was reduced:

> [The council and I] … set up terms of reference that define how family council is going to operate … [We also wrote] out a profile of what the chair, vice chair, …[and] secretary's responsibilities and characteristics should [be] in that role. [We] defined the chair's role as being somebody who has the whole facility's well-being in mind, and who has a track record of good collaborative skills … [so we] made sure that the council [was] behaving properly. … because [confrontational people like in this example] are a [family council's] worst enemy, because they can give [council] a bad reputation. *(Advocate 2-1)*

There was considerable variation in terms of how participants defined the most appropriate time and location for council meetings, as well as council structure (i.e., joint vs. separate family and resident councils). However, most participants agreed that trial and error were required to find the 'right' combination of time, location, and structure, to maximize effectiveness of councils. For example, one resident described meetings under one hour as most productive, as otherwise 'it gets to be a gabfest if you do it much longer: it focuses your thoughts [and] makes the chair focus their thoughts' *(Resident 1).* Additionally, some participants believed a combined family and resident council to be most effective in their LTC home community (e.g., *Resident 2*), whereas other participants believed their LTC homes were most suited to separate family and resident councils, such as in *Leader 4*'s example:

> I would struggle to visualize a combined council. We have a very active resident council. It's very popular. They love coming to it, they like to talk about the food a lot … but you can't see a family council wanting to sit through [that], …and go over the menu again. Whereas the residents, that's really important to them. So they need to be able to have that time to talk about what's important to them. …Both parties need a venue where they can really transfer and receive information but in a very different way *(Leader 4)*

One of the most-discussed aspects of council effectiveness was their status as a self-determining group. Participants perceived the most effective councils to be self-determining, that is, councils were run independent of LTC home staff/leadership. Many participants (particularly family members) described situations where they felt unable to express concerns, ideas, or critiques about their LTC homes when council meetings were run by staff/leadership:

> I really wanted to be an active part of [my husband's] care. … and I was really looking forward to [the first family council meeting]. I got there … and I had a list of things that I wanted to discuss, and it was run by the staff, and it was … 40 minutes [long]! My God, I was so deflated. I was like, 'why do you even call this a family anything'? It was all staff and there was maybe a little wee sliver in there [for family input or engagement]. … I just remember feeling … totally deflated, what a waste of my time. *(Family 1-3)*

One family member described the challenges of trying to run their family council independently after the new LTC legislation was passed in November (2022): 'It's the law that family councils have to be run independently of the care employees. We're getting a lot of push-back on that. [LTC home leadership] don't want to let go' *(Family 1-4).* Another family member described having to run council meetings off site due to the LTC home leadership refusing to allow the council to operate independently:

> Unfortunately, in my family council, we didn't have an operator who was prepared to listen, to open up and hear what had to be said, and to try to work with the families to come to some resolution. The operator [at our LTC home] was constantly trying to marginalize us, trying to basically just get rid of us. … Right from the get go, they said, no, this is our facility. You will do what we instruct you to do. We will set the terms of reference. We will come to each and every one of your meetings. That's the way it is if you're going to operate your council here. So basically, we were forced to take our council off site and find a place where we could meet so that we could discuss privately… it was difficult. *(Family 2-1)*

Recruitment and engagement

According to participants, effective councils rely on continuous efforts to recruit and engage new council participants, especially in the context of high resident turnover rates.

> Successful family councils [must] have a strategy to keep building membership. Turnover in long-term care is much different than it was 15 years ago. Residents don't live [forever] and so it's hard to sustain [council] membership, let alone build it. But that has to be an absolutely critical part of a family council's strategy. How are we going to inform people about what [councils] do [and] get them involved? [We need to] make sure [families] understand that they have a voice. *(Advocate 2-1)*

Many LTC homes struggle with recruiting council participants, which can affect representation, and thus influence council effectiveness. 'We have really struggled to get active membership in the family council. Across both sites, I think the most members we've ever had at a family council meeting is under 10, so that's 200 residents and under 10 families coming in to participate.' *(Leader 5).* Some family members described LTC staff/leadership actively ripping down council posters and refusing to allow councils to advertise in the welcome package. '[Leadership] didn't want anything to do with the family councils. It was just like, 'you guys are a pain, you're policing us, we don't need you, go away.' And they would do things like rip down posters from our meetings so that people wouldn't see [we were] having a meeting.' (*Family 2-1*). These comments underscore the importance of not only allowing, but also supporting the council recruitment process in order to increase the number of residents and families receiving information about councils.

'With the new regulations … I can pass anything to [the LTC home leader] and ask [them] to share it with all the residents' families, and it's being done. … We had our pamphlet and during

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the admissions, they would pass this out to the new families. … that's how we're encouraging it to be done now, so that the message gets out to the family right away on admission. And we don't reach out right away. We give it 10 days or so, and then we reach out and explain that we have a family council, and that part's working well because it is educating people.' *(Family 2-2)*

In addition, participants pointed out that celebrating council successes can help to encourage council participation:

> If a decision or if input was provided [by the council] … and then that decision was made and then there was an outcome really celebrating that…that's really going to help build a trust in the whole process. 'Oh, this actually works.' It's going to help with engagement. People are going to be more likely to engage if we build on those successes. *(Advocate 1-1)*

Council leadership

Councils led by skilled and experienced council members were considered by participants to be most effective. Effective council leaders keep council meetings organized and hold LTC leadership accountable:

> A big factor is the leadership capacity of family council executives. Our family council …run their own election with some staff support. They also have executive members [who] hold us accountable in a way that they create a timetable for anything that we talked about. And they really keep track of everything. They monitor the time so they really run family council like how they run a business. *(Leader 3)*

Entering the LTC system was described by participants as a complicated and challenging learning process fraught with deep emotions. Effective council leaders need to be able to provide support to new members in their learning process and education on LTC legislation. One family member described their attempt to navigate a safety concern for their father, who resided in a shared room. The family member described bringing up the issue with care staff repeatedly without resolution, until the family council leader provided guidance on how to advocate with management. The family member described the issue being promptly resolved after following the advice of the council leader: 'What I took from that is that where there are family councils having the information or somebody who has access to information to tell you what steps and what the law says is vital because I was just at my wit's end. I mean, I understand that these [residents who were causing the safety concern] are not well, but I wanted to look after my dad.' (*Family 1-1*).

Family members also expressed concern about the loss of knowledge and experience when a family council member's relative dies. In some LTC homes, if a family council member's relative dies, they are no longer permitted to attend council meetings: 'There was pushback from the management over [being allowed to stay on family council…], because they felt that when your loved one passed away, you should step away and be gone.' *(Family 2-1).* One advocate provides an example of how their past experience could have benefitted the council had they been allowed to continue:

> I went through my mom's Alzheimer's for all those years, and I used to learn little tricks [like setting up a calendar of what activities she did during that day] so [the calendar] became her memory [substitute] for the day. I would share that idea with other families [who had loved ones in care with Alzheimer's]. Little tricks that would make things better, and if I can't belong to that council, I can't share that kind of thing. *(Advocate 2-1)*

For councils that have difficulty operating independently, strong leadership is particularly important to advocate for a council's right to self-determination, as one family member describes: 'Whoever chairs a family council really has to be a tough cookie and push back.' *(Family 1-4).* One LTC home had challenges finding strong council leadership and organized for a graduate student to come and volunteer to help to support council:

> She was fantastic. She facilitated a number of open houses, gathering people together …What we wanted her to do was help the families get [council] back up and going and define a term or reference, talk about how you would communicate with each other, what are the agendas, and what are some appropriate things that [council] can do. She did that for 5 months, she was with the families at the council meetings, trying to encourage them to step into sharing and coming up with ideas. *(Leader 5).*

Culture and attitude

Many participants reported persistent misconceptions in the LTC community about the purpose of councils, which inhibited council effectiveness. For example, one leader explained that the misconception of family councils as a place 'where you go to complain' dissuades participants from engaging with councils *(Leader 5*). Participants also pointed out misconceptions among the LTC leaders. One family member, for example, described LTC leaders as 'on guard' in their interactions with the family council: 'First encounters with [LTC leaders] are not adversary, but they're on guard always. When you approach them, no matter how urgent your concern, no matter how valid it is, no matter how compassionate, they are always on guard.' (*Family 1-2).* Another family member reported trying to address systemic concerns with LTC staff/leadership, but 'the problem was we couldn't even get the operators to pay attention to a lot of the family councils, they didn't want anything to do with the family councils.' (*Family 2-1)*

In LTC homes with persistent misconceptions about councils, the resulting cultures of distrust and negative attitude prevented LTC staff/leadership and council members from establishing a shared vision together. Instead, family members noted the fear of reprisal prevented council participants from voicing their concerns in LTC homes where negative attitudes and adversarial cultures prevailed:

> I would say probably 60% of the people that were in our [family] council would not bring forward a concern directly because they were so fearful of reprisal against themselves in how they [would be] treated if they complained, or worse any retaliation against their loved one. … 80% or more of people have dementia. And for a person with a loved one with dementia, it is frightening to walk out of that facility and wonder what is happening behind closed doors. *(Family 2-1)*

Participants noted that this fear of reprisal prevents a collaborative culture between staff/leadership and residents/families, which can prevent councils from collaborating and functioning effectively.

Resources and supports

Participants highlighted the importance of having access to key resources and support to operate effectively. Key resources included having a private space for councils to meet and equipment to run the meeting (e.g., tables and chairs, microphone and speaker, etc.). For residents, having a designated staff member was considered essential to accommodate residents with disabilities and other barriers to participation. Designated staff members are required to help set up meetings (e.g., clear space at a table, set up a microphone, etc.) and to take and distribute meeting minutes.

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Participants felt that having a staff member helped support council effectiveness: 'The recreational therapist would write up the minutes and send them out to [resident council members] and give a copy to the manager…this was resulting in some changes' *(Resident 2)*.

Family council participants also reported benefitting from virtual meetings, a method that proliferated during the pandemic visitation restrictions. One family member described an increase in attendance at council meetings held virtually:

> One of the upsides to the Covid experience, there were a fair number of resident and family council meetings held by Zoom. And suddenly family members who were on the prairies on the East Coast somewhere in the States could take part …. Zoom meetings actually turned out to be well attended by people who wouldn't normally be able to attend. … [The council participants] were able to hear what was going on directly from management, and if they had any concerns, they certainly could speak up and comment. *(Family 2-2)*

An additional key resource that affected council effectiveness was a connection to the regional associations of LTC councils (an association that represents the collective voices of LTC councils across British Columbia). The regional associations consisted of willing and experienced experts who helped councils not only to form and start operating, but also provided individual councils with specific education about key pieces of legislation (e.g., the Community Care and Assisted Living Act and the Residential Care Regulation), and about the common systemic issues experienced by multiple LTC home communities:

> Through the [Regional Association of Family Councils] we learned a tremendous amount because there were some really good experienced people that had been involved in family councils for a couple of years. We would meet and we would discuss, and very quickly we found out that we were not the only facility that was [encountering] these numerous problems. *(Family 2-1)*

Discussion

Canadian LTC homes are experiencing a trend of increasing medical complexity of residents and shorter lengths of stay (Estabrooks et al., 2020), which, according to our findings and existing literature (Baumbusch et al., 2022), can influence council effectiveness due to decreased participation in councils and increased turnover rates of both residents and family members. Although these are non-modifiable factors that can hinder council effectiveness, our study identified various modifiable factors that can be acted upon to increase council effectiveness.

First, communication was found to be paramount to effective councils. Our findings supported the existing literature on the characteristics of effective teams, which determined establishing a consistent and defined avenue for communication can foster trust and collaboration (Baker et al., 2006). Example communication tools used by participants included Facebook groups, emails to all families/residents, a tab on an LTC home website, and poster notices in the LTC home. The communication between councils and LTC staff/leadership (and vice versa) must also be transparent (including both positive and negative feedback). Transparent communication (achieved by being forthright and clear about actions and decisions) has been shown to build trust, collaboration, accountability, and respect (Brenner et al., 2022; Bridges et al., 2021), which, according to our results, decreased family member and resident fear of repercussions of speaking up. Decreased fear of repercussions can increase the likelihood of councils speaking up about concerns and ideas, which can, in turn, promote constructive discussions regarding quality improvement in the LTC home. According to our findings, integrating positive feedback (as opposed to focusing only on negative feedback) into conversations with staff/leadership promoted collaborative relationships between the council and staff/leadership. Additionally, our findings emphasized the importance of timely and appropriate follow-up on issues raised by councils and/or staff/leadership. Communication that is two-way or closed-loop (i.e., the message-receiver confirms to the message-sender that they have received the information (Diaz & Dawson, 2020)) can foster timely follow-up. Bi-directional feedback (i.e., when feedback is given from councils to staff/leadership and from staff/leadership to councils) can increase effective communication across power differentials (Myers & Chou, 2016). Furthermore, according to our participants, inviting staff/leadership to attend council meetings promoted council effectiveness by opening an avenue of communication and presenting opportunities to build relationships between council and LTC staff/leadership. The extension and acceptance of an invitation can signify willingness to collaborate and to understand the perspectives and experiences of the council, staff, and leadership. Having respect for others' roles is essential for good working relationships that recognize equality (Sargeant et al., 2008).

Participants also emphasized the importance of having structured meetings to facilitate accountability and collaboration by creating space for respectful dialogue where families and residents can bring up issues that are important to them. According to previous research on effectively functioning teams, a structured and systematic approach to meetings that is aligned with what matters to the whole team is essential (Norenberg, 2020). According to our findings, following a code of conduct with well-defined roles was thought to promote collaboration and prevent intra-council conflict. In addition, having meetings for a defined period at an accommodating time of day (e.g., not running into resident meal times) was perceived to facilitate recruitment of council participants.

The self-determining status of councils was also viewed by the participants as vital for their effectiveness. According to the findings, councils that were run by staff/leadership (or family forums that are mislabelled as family councils) prevented council participants from openly discussing their concerns and ideas without fear of repercussion. When LTC staff/leaders actively dissuade councils from operating independently, a conflict of interest is created that hinders councils from being able to operate to their full capacity. Recent data from British Columbia show that over half of family council meetings were still chaired by staff members (Baumbusch et al., 2022), which, according to our participants, was a significant barrier to effectively functioning as a council.

Participants pointed out that ongoing recruitment were necessary to maintain council participation in light of the high resident and family turnover rates, which was echoed in the study by Baumbusch et al. (2022). Our findings indicated that continuous council involvement can help to ensure that issues brought forward by the council are representative of the voices of residents and families in the LTC home community. Participants identified a range of recruitment strategies, such as providing newly admitted residents and families information about councils; encouraging participation in councils via word of mouth; publicizing meetings in newsletters/mail outs/email notices/posters; and showcasing successful outcomes resulting from council engagement. According to our findings, celebrating successful outcomes, even 'small'

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ones, can build trust in the council process, which encourages council engagement.

Participants in our study also emphasized the importance of having knowledgeable and experienced council leadership who provided councils with structure, organization, accountability, and guidance. Participants felt that being informed about the LTC system, LTC legislation, and the LTC home community helped council members to voice concerns, and suggest solutions. This educational element of councils was considered a significant benefit of having effectively functioning councils (Baumbusch et al., 2022). To retain experienced and knowledgeable council members, some participants suggested allowing family members whose relatives have died to remain as 'non-voting' members.

A key challenge raised by participants who reported difficulties in establishing effective councils was the presence of distrust and negative attitudes towards LTC councils. Our findings supported the existing literature citing the creation of collaborative trust-based cultures and attitudes as vital for establishing effective teams (Baker et al., 2006; Norenberg, 2020). Although resident and family engagements are considered an essential component of creating a collaborative culture in LTC (Duan et al., 2021), misconceptions about the function and role of councils remain pervasive and can prevent councils from operating effectively. The existing evidence support our findings that LTC staff/leaders played an essential role in dispelling existing misconceptions and working towards establishing a collaborative culture between staff/leadership and residents and families (Baumbusch et al., 2022; Duan et al., 2021). Rather than working towards a shared vision together, an adversarial culture between councils and LTC staff/leadership created an 'us versus them' sentiment, preventing councils from communicating, collaborating, and functioning effectively. Participants suggest publicizing positive council outcomes (exemplifying collaborative and effective council-leadership relationships) could help to address misconceptions on a larger scale.

Finally, our results underscore the importance of having access to appropriate resources and support for council meetings (including access to a private space, tables and microphones, virtual meeting rooms, and staff support for resident councils) and having access to resources at the regional level (which can provide a broader perspective and education to empower local councils with knowledge and tools). Virtual access to council meetings is a key resource for engaging family members who live far away from their loved ones (Baumbusch et al., 2022). As per the participants, providing practical tools to increase the ability of councils to communicate with each other and with staff/leadership was essential to increasing engagement with residents and families through councils. This type of engagement is known as an essential element in creating collaborative LTC cultures (Duan et al., 2021).

Implications

Our team used the empirical findings described above to develop a preliminary instrument that operationalizes council effectiveness (see Supplementary Appendix 1). The preliminary instrument has undergone extensive review and revision by all team members. At the care home level, councils can use the instrument to gain a comprehensive and systematic understanding of modifiable factors that could be acted upon and advocated for that could increase council effectiveness. At the provincial and regional levels, the instrument can be the stepping ground for establishing a provincial and a regional baseline for LTC council effectiveness that can be tracked over time and across contexts to ensure LTC homes in British Columbia move towards collaborative cultures that regularly and systematically engage residents and families.

The current instrument consists of 34 Likert-type questions, capturing the six domains of modifiable effectiveness factors, in addition to a global effectiveness question. Future work on the instrument will focus on its' validation, starting with content validity (Hubley & Zumbo, 2011). Once a valid instrument is in place, a provincial survey of all LTC councils will be conducted to establish a baseline with respect to council effectiveness and to use this data to identify a way forward for supporting the work of the councils.

Strengths and limitations

With findings based on a small number of participants, this study was not designed to produce generalizable results. Additionally, due to recruitment challenges, we were unable to include the perspectives of policy-level LTC decision makers in this study. However, by rigorously analysing the rich conversations we had with participants, our results were used to design a preliminary effectiveness tool that will undergo validity testing to account for these limitations. A further strength of this study is the valuable input of our patient partner knowledge-user research team members, who provided their expertise, input, guidance, and feedback throughout each stage of this study.

Conclusion

This study drew together diverse perspectives from LTC home communities, including residents, families, leaders, and advocates, to elucidate the underlying determinants of family and resident council effectiveness. While some non-modifiable factors were identified as consistent barriers to council effectiveness, the presence or absence of other modifiable factors – communication, structure, recruitment/engagement, council leadership, culture/attitudes, and resources/support – served as facilitators or barriers to effectively functioning councils. The identification of these modifiable factors informed the development of an evaluative tool aimed at operationalizing the concept of council effectiveness, thereby enabling a comprehensive and systematic understanding of the required changes essential for nurturing effective council dynamics within LTC homes at the local, regional and provincial levels.

Supplementary material. The supplementary material for this article can be found at http://doi.org/10.1017/S0714980825000029.

Acknowledgements. The authors would like to thank the long-term care residents, family members, advocates, and leaders who took valuable time out of their busy lives to contribute to this work. Additionally, the research team would like to acknowledge Dr. Aleksandra Dulic for her mentorship support of doctoral trainee, Amira Ahmed, throughout this project.

Funding. This research is funded by the University of British Columbia Health Innovation Funding Investment Award – Healthy Aging Stream (F23-02838) and an Ad-Hoc Research Enablement Fund (F23-04254).

Competing interest. None to declare.

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