

Whom Do I Trust to Represent Me? Long-Term Care Resident and Family Perspectives on Legitimate Representation

En qui puis-je faire confiance pour me représenter?
Point de vue des résidents en soins de longue durée et de
leurs familles sur la représentation légitime



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Abstract

Introduction: Public engagement in long-term care policy making in Canada has primarily focused on “intermediary agents” who speak on behalf of long-term care (LTC) residents and their family caregivers. Yet the legitimacy of these intermediaries, as perceived by those they represent, has gone largely unexplored. This study examines LTC resident and family perspectives on who can legitimately represent them in LTC policy making.

Whom Do I Trust to Represent Me?

Methodology: We used an interpretive description design, drawing on semi-structured interviews with LTC residents and family caregivers in Ontario, Canada. Data were analyzed using inductive thematic analysis.

Results: Eighteen interviews were conducted with 19 participants. Three key characteristics of legitimate representatives were identified: (1) willingness to act in the best interests of residents and families, (2) having the necessary skills and capacity to participate in LTC policy making and (3) engaging directly with residents and families.

Conclusion: Governments and civil society organizations seeking to establish and maintain legitimacy in the eyes of LTC residents and family members can pursue this goal by supporting intermediaries who mirror the identities or experiences of those they represent, who are dedicated to serving their interests and who routinely and directly engage with them to understand the realities of LTC.

Résumé

Introduction : La participation du public à l'élaboration des politiques de soins de longue durée au Canada a surtout été axée sur les « agents intermédiaires » qui parlent au nom des résidents en soins de longue durée (SLD) et de leurs proches aidants. Pourtant, la légitimité de ces intermédiaires, telle qu'elle est perçue par ceux qu'ils représentent, demeure largement inexplorée. Cette étude examine le point de vue des résidents en SLD et de leurs familles quant à savoir qui peut légitimement les représenter dans l'élaboration des politiques.

Méthodologie : Nous avons utilisé un modèle de description interprétative, en nous appuyant sur des entrevues semi-structurées avec des résidents en SLD et leurs proches aidants en Ontario, au Canada. Les données ont été analysées à l'aide d'une analyse thématique inductive.

Résultats : Dix-huit entrevues ont été menées auprès de 19 participants. Trois caractéristiques clés des représentants légitimes ont été identifiées : (1) la volonté d'agir dans l'intérêt supérieur des résidents et de leurs familles, (2) avoir les compétences et la capacité nécessaires pour participer à l'élaboration des politiques en matière de SLD et (3) s'engager directement avec les résidents et les familles.

Conclusion : Les gouvernements et les organisations de la société civile qui cherchent à établir et maintenir leur légitimité aux yeux des résidents en SLD et de leurs familles peuvent poursuivre cet objectif en soutenant des intermédiaires qui reflètent l'identité ou les expériences de ceux qu'ils représentent, qui se consacrent à servir leurs intérêts et qui communiquent régulièrement et directement avec eux pour comprendre les réalités des SLD.

Introduction

Governments across Canada have recognized public engagement (PE) as an integral part of health policy making (Abelson and Eyles 2004). Compared to traditional approaches to policy making, where the public remains a passive beneficiary of policy decisions, PE has various

anticipated benefits, including developing better-informed policies and enhancing the perceived legitimacy of those decisions (OECD 2009). In Ontario, the *Patients First Act* (2016) and the establishment of Ontario Health Teams align with the active engagement of patients and communities in health system planning, design and governance (Government of Ontario 2024). The value of public input has also been recognized in Ontario's long-term care (LTC) sector, although the direct involvement of LTC residents and families is in its infancy (Frank et al. 2023).

Residents and families can join a residents' or family council in their individual home to advocate for their needs; however, their roles are generally limited to the personal care or facility level, such as care conversations, planning social activities and meal and laundry services, and do not extend to policy making (Hylmar 2016). Instead, various individuals or organizations are often observed proposing policy solutions for the health and well-being of LTC residents (Barbieri and Ghibelli 2017; You and Abelson 2022). These entities, which can be referred to as "intermediary agents," act as a bridge between policy makers and LTC residents and families, representing the interests of residents and families in policy making (Falanga et al. 2021; Keogh et al. 2021). Intermediary agents are not limited to a single type of role or profession within the sector and may hold multiple identities, including LTC residents (e.g., a resident who also serves as an organizational representative of seniors) or family members (e.g., a family member who is a geriatrician) (Barbieri and Ghibelli 2017).

The reliance on intermediaries in LTC policy making can be attributed to the prevailing regulatory environment prioritizing safety concerns over residents' autonomy (Frank et al. 2023). Additionally, challenges faced by LTC residents, such as physical and cognitive frailty (Holroyd-Leduc et al. 2016), constrain their ability and willingness to contribute directly to policy making (Mattila et al. 2017). These unique factors in the LTC sector provide self-claimed representatives with active and expanding roles in policy making, often without a formal authorization process (e.g., elections) (Leardini et al. 2019). While the engagement of intermediaries can ideally yield similar benefits as PE (Martinez and Kohler 2016), it does not automatically legitimize their representation (Montanaro 2012).

Political representation and related concepts of legitimacy and authorization are complex concepts with a wide range of interpretations (Arnesen and Peters 2018; Rehfeld 2011). For instance, descriptive representation, where representatives mirror the social identity or experiences of those they represent (e.g., female representatives representing female constituents) (Mansbridge 1999) may compromise substantive representation, which focuses on actual policy alignment with constituents' interests (Arnesen and Peters 2015). Furthermore, the debate extends to whether substantive representatives should act as delegates, following constituents' preference, or as trustees, using their own judgement to determine the best action (Dovi 2018). Given these multiple meanings of representation, this study adopts Suchman's (1995) view of legitimacy: "a generalized perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs, and definitions" (p. 574). Legitimacy is subjectively

constructed (Arnesen and Peters 2018) and the perspectives of those represented serve as the baseline for assessing the legitimacy of representation (Leardini et al. 2019).

Despite the active role of intermediary agents in LTC policy making in Ontario, their legitimacy, as perceived by those they represent, remains largely unexplored. This research examines the perspectives of LTC residents and their families on who they believe can or should represent their interests in policy making.

Methodology

Design

This study uses an interpretive description design (Thorne 2016). This approach is commonly used to develop knowledge relevant to clinical and other applied health contexts. Interpretive description recognizes that understanding of realities is co-constructed between the researcher and participants (Hunt 2009).

Sampling and recruitment

Purposive sampling was used based on the following criteria: (1) age 18 years or older, (2) personal experience as a resident or a family caregiver of a resident in LTC facilities in Ontario and (3) English fluency. Participants were recruited through e-mail outreach to organizations across Ontario that closely collaborate with or advocate for LTC residents and family caregivers, online advertisements on Twitter (now X) and LinkedIn and snow-ball sampling through participant referrals. The online advertisements generated numerous potentially bogus responses (e.g., brief e-mails lacking detail about respondent experience with LTC and directed inquiries about the study honorarium) and this recruitment approach was stopped immediately. The recruitment focus shifted to direct contacts with organizations known to collaborate with LTC residents and family caregivers, asking them to share the recruitment information through their networks. By employing this approach, we were aware of the possibility that these organizations, which themselves can be considered intermediaries, may have shaped our results.

To appreciate participants' time, an honorarium of \$25 was provided in the form of a gift card or mailed cheque. Recruitment and data collection ceased when the lead investigator (JY) determined that the study had reached a point where data analysis had the potential to provide new knowledge to extend existing evidence and adequate information power was established. Ethics approval of the study was obtained in November 2022 from Hamilton Integrated Research Ethics Board (reference no. 2022-15150-GRA).

Data collection

One-on-one semi-structured interviews were conducted, except for two family caregivers who requested to participate together. Interviews were conducted in English via Zoom, digitally recorded and transcribed verbatim. Reflective notes were taken during and shortly after the interviews. The interview transcripts and reflective notes were stored in the NVivo data analysis software.

The interview guide included general questions, enabling interviewees to freely discuss characteristics of good intermediary agents in policy making. Probes were used to elicit and clarify the interviewees' responses. The concept of "intermediaries" was introduced at the beginning of each interview as those who speak on behalf of LTC residents and families in Ontario's LTC policy making. The interviewer provided examples (e.g., "they can be professional groups, labour unions, charities, business associations or academic experts") without referring to specific organizations. When asked for examples, the interviewer named some active intermediary agents in Ontario and continued to discuss their characteristics.

Data analysis

Interview data were analyzed using inductive thematic analysis procedures (Maguire and Delahunt 2017). The method of constant comparison was used, which encourages researchers to remain skeptical and continuously question the initial conceptualizations of the collected data to obtain a coherent and rich interpretation about the phenomenon of interest (Hunt 2009; Thorne et al. 2004).

Results

Eighteen interviews were conducted with 19 participants. The interviews lasted 45 to 70 minutes. Participants included 17 family caregivers and two LTC residents with experience in Ontario LTC facilities.

Three unifying themes were identified describing the core characteristics of trustworthy intermediaries. Each theme is discussed below, with illustrative quotes attributed to different types of respondents (i.e., R for resident or FM for family member + participant number).

Before delving into core characteristics, participants discussed the role of intermediaries. They acknowledged the importance of representation for LTC residents and their families, particularly when self-advocacy is challenging. They noted various barriers to advocating on their own behalf, including residents' cognitive impairment and family members' commitments, such as day-to-day caregiving for the residents, jobs and childcare.

One participant explained:

The average length of stay for residents in long-term care is 18 months. They're so much more physically and medically compromised when they move in. So as a result ... they're turning over so quickly that you don't – you know, they certainly can't organize and get together and do anything So we need to have someone that speaks for us. (FM8)

Participants also frequently mentioned the fear of repercussion when voicing their concerns, underscoring the need for others to speak for them. One participant described "see[ing] it in the family council when people will complain about something and they're like, 'But don't say I said it'" (FM5).

Despite acknowledging the importance of intermediaries' role, participants expressed uncertainty about the alignment of intermediaries' interests with their own, prompting questions such as "whose interests are they acting on?" (FM1).

Theme #1: Trustworthy intermediaries are willing to act in the interests of LTC residents and families

Participants emphasized the importance of intermediaries' sincere willingness to improve LTC policies and systems. One participant described this as, "you have to have that passion about it to say, you know what, I'm going to be in this place too at some point, hopefully, and I want to make sure I'm taken care of" (FM5). Participants differentiated this dedication from that of intermediaries who consider their roles as a "stepping stone" to future careers (FM2) or who would "walk away" when offered better terms and pay (FM10).

Participants also emphasized the importance of intermediaries who share the social identity of residents and/or family members, suggesting that intermediary groups include LTC residents or their families "[in] some proportionality of the representatives on a committee" (FM17) to provide important perspectives of "those who are actually living [in LTC environments]" (FM15). To this end, some participants proposed a form of "direct engagement" (FM1), for which governments "empower" them (FM3) and host government-led "direct engagement with a representative of every resident of a long-term care facility to provide annual feedback" (FM11).

Concerns were expressed over intermediaries who primarily support the interests of different groups rather than the interests of LTC residents and their families (e.g., health professionals, researchers or LTC home operators). This misalignment was worrisome, as the priorities of these intermediaries may deviate from those of residents and families. For instance, one participant mentioned that intermediaries with a labour perspective might be "too narrowly focused" on financial investments, increased staff and training as opposed to the care outcomes for LTC residents (FM17). In this regard, some participants viewed intermediaries' past actions and accomplishments as important indicators of their genuine passion and dedication to represent them, as described by this participant:

They can say that they represent the seniors or long-term care resident, but if I want to see if an individual or an organization, whether they can truly represent [us] or do what they say, I will look at their credentials What have they done in the past? (FM16)

Notably, participants want intermediaries to be more engaged in advocacy efforts with a "rock the boat" stance (FM8), rather than merely behaving like a liaison. These perspectives were prominently voiced in relation to government-funded intermediaries who may feel limited in speaking out or challenging the government, therefore inhibiting policy change. As one participant described:

[Anonymized] are into gradual, easy steps, trying to be gentle and positive and not antagonize. There are situations where they seem to want to tone things down so that you don't get confrontational questions or confrontational statements being made [T]here's no way that the [anonymized] can become self-supporting to be truly independent of government [or] other voices. (R2)

Intermediaries taking on a "middleman" or "liaison" role (FM8) rather than being LTC advocates generated concerns among participants who perceived that their voices are "purposely ignored" (FM10), "filter[ed]" (FM4) or "stifle[d] in the wilderness" (FM10) by intermediaries. Participants felt that some intermediaries intentionally avoided welcoming and listening to their concerns by not clearly communicating the existence of family council meetings to family members (FM12), or by directing family members to "talk" about their complaints rather than "write" them down (FM9). Accordingly, many participants identified the importance of intermediaries being free from potential conflicts of interest and hidden motives. This emphasis was prominent when discussing the for-profit industry:

[For-profit industry actors are] motivated by their bottom line ... [and] some of the things that they do are based on economies and efficiencies Their opportunities were there to eliminate costs [for] them: maybe it's in the cleaning and painting, the maintenance, things like that, that they don't end up spending the money. (R2)

Finally, participants identified the provision of accurate and balanced information and perspectives as a sign of information not being "compromised ... to fit the political reality" (FM1). The need for transparency in conveying information was also stressed to ensure their interests are accurately represented with "a great deal of integrity ... [rather than] interpret[ing] it the way they wish" (FM4).

Theme #2: Trustworthy intermediaries have the necessary skills and capacity to participate in LTC policy making

Participants underscored the importance of intermediaries having the necessary knowledge, skills and capacity to be able to contribute effectively to policy making. One participant described the importance in this way:

Politicians do not listen to individuals [Y]ou need to have someone who represents a larger group ... being communicated with on a regular basis, sending those weekly information bulletins, responding positively to personal enquiry, leading workshops, organizing – that is the person that has a better chance of being actually heard. (FM2)

Participants valued a range of professional knowledge and expertise, such as geriatrics, nursing, dietetics, pharmacy, human rights and disability laws, space design and change

management. One participant stated, “I can accept when people with learned backgrounds, who have studied epidemiology, who have studied medicine, who know about healthcare in terms of, you know, they are legitimate professionals, right.” (FM10).

Participants also perceived the lived experience of LTC residents and their families, as well as the first-hand knowledge of front-line workers, as an important form of knowledge that reflects the realities of LTC, ensuring intermediaries have an “accurate picture of what should happen” (FM13). This knowledge was perceived as essential compared with “findings from other reports that may not have the true understanding” (FM16). Most believed that the LTC policies and programs do not accurately reflect “the current realities” (FM1), including “the daily frustrations [of residents]” (R2) and “the boots-on-the-ground” perspectives (FM6). In this regard, some participants explicitly valued lived experience over professional knowledge. As one participant stated, “We treat the doctor as God, we listen to everything they say. Right. But then the doctor may not be aware of ... very small things that family members know about the residents that the doctors don’t” (FM16). While valuing lived experience, participants emphasized the importance of intermediaries being able to differentiate “the personal story with the overall message” (FM2) and address the shared needs and concerns common to all individuals in LTC homes.

Participants perceived adequate resources and skills as key enablers in making their voices “visible to public” and being able to “put a bit of heat on decision makers” (FM11). This was described as having effective communication skills to deliver clear and concise messages that can be understood by both the public and government officials (FM2), “understanding of all the factors at play there [bureaucracy of the health system]” (FM11) and “networking with people [key LTC stakeholders]” (FM17). Adequate “operating funds” (FM12) were identified as important support for this work, rather than relying solely on volunteers.

Participants who emphasized the importance of lived experience favoured intermediaries with this experience over those trying to attain the level of policy resources and capacity of other well-resourced entities (e.g., LTC industry). As one participant articulated:

I don’t expect ... their job ... to work magic and come up with a lot of change overnight. If they put forth 50 things in front of government and two things were truly addressed, I would think, “OK, that that’s good progress,” because I know it’s not realistic to think you get 100 percent. (FM14)

Theme #3: Trustworthy intermediaries effectively engage with LTC residents and families

Participants emphasized the importance of engaging with intermediaries through regular, two-way dialogue as a crucial aspect of their trustworthiness. As one participant stated, “I could communicate my personal opinion, I could say – have you considered this? As long as I am not dismissed, then that person still has my respect and I trust that that

person is speaking on behalf of the greater good” (FM2). Conversely, participants reported distrust in intermediaries who display a lack of interest in hearing from residents and families, describing experiences in which two-way communication was absent:

They were in a communicating or telling mode, not asking mode I’m not asking for direct access to the policy decision maker, but there has to exist some kind of a vehicle through which voices are heard. (FM10)

Participants found that two-way communication helps intermediaries to accurately represent their interests. As one participant stated:

These people should be in communication directly with residents. So that they’re coming from that, and they can go ahead and say, “These are what the residents’ opinions are, and these are what the residents would like to see happen.” And be able to speak forthrightly on that. (R2)

Even with available opportunities for interaction, participants want intermediaries to gather input from a wide range of individuals. Participants emphasized the diverse and heterogeneous care needs of LTC residents and felt that intermediaries communicating only with specific segments (e.g., those who are frail) are not effective representatives. One participant stated, “I’d mainly worry about them speaking, because they all make assumptions about your level of cognition... . [O]ne person cannot just represent someone like me with cognitive skills and then someone who needs a feeding tube” (R1). Another participant echoed this perspective:

If the government assumes long-term care is for people who are physically and mentally compromised to the point of not being able to speak for themselves, they go to organizations that represent only those groups. And they will get the perspective of only those groups So if there were an association that very proactively reached out and made a point of getting the perspectives of underserved ... I would trust them. (FM15)

Regarding the pursuit of diversity, participants emphasized the importance of intermediaries’ proactive outreach to those who may be less inclined to speak up, including “the silent majority” (FM10) and “the perspectives of underserved” (FM15). One participant explained:

You get the people [who] complain because they’re angry enough to make the effort [Y]ou’ve turned off a lot of people who might have really good ideas and want

to move things forward or whatever. So, you've got to really encourage everyone and meet them where they're at and really try and bring them out. (FM8)

Participants also highlighted their preferences for particular methods of engaging with intermediaries. One participant noted, "I don't find questionnaires that fulfilling, I like the one-on-one Zoom calls ... because I think that's when people really listen to you." (R1). Another participant reaffirmed this idea: "If we were to try to write this in the e-mail format to have our discussion, you'd probably spend two weeks putting it together to write it back-and-forth It's not as efficient as everybody claims." (FM1). Other participants emphasized the need for a safe way of communicating, "They have meetings with residents and goes[sic] over issues, so there's a system in place. But when it comes to something that, what's the word, controversial as what I raised, I'm inclined to think I might do something more anonymous" (FM4).

Discussion

Discussion of the findings in relation to relevant literature

Our results have implications for common PE practices in current LTC policy making. The importance of having intermediaries who can represent the interests of LTC residents and families in situations where they are unable to speak for themselves is recognized, although concerns arise regarding the alignment of intermediaries' interests with those of LTC residents and families, which in turn affect the level of trust in their representation. The emphasis on trust in our findings is unsurprising, as trust forms the basis for constituents' willingness to endorse the legitimacy of their representatives (Hegtvedt 2015; Moreno-Luzon et al. 2018).

Our findings prominently highlight the value of intermediaries who either mirror the identity of or possess experience as LTC residents or family members. On the surface, this resonates with the concept of descriptive representation, frequently linked to perceived legitimacy within politically disadvantaged populations (Arnesen and Peters 2018). However, our findings also offer insights into substantive representation, which is often observed together with descriptive representation but brings a stronger focus to the policy outcomes that arise from representation (Hayes and Hibbing 2017). Our study participants connected the characteristics of substantive representation with intermediaries' willingness and capacity to act in their best interests as a means to drive actual benefits, rather than the characteristics of descriptive representation, in which intermediaries' identities merely matched those they were representing (e.g., average or randomly selected entities that have the identity or experience of LTC residents or family members).

Study participants' emphasis on intermediaries' identities and experiences partially echoes tensions observed in previous studies between professionals' and LTC residents' views regarding what is best for residents (Nelson et al. 2005) and perceived conflicts between residents, families, staff and institutions regarding residents' safety and quality of life (Armstrong

2018). However, with the exception of entities closely associated with the for-profit industry, participants regarded the lived experience of LTC residents and families as complementary rather than contradictory to the expertise of other stakeholders (e.g., medical professionals).

Participants perceived that effective two-way communication between intermediaries and LTC residents and families can function to enable and facilitate the desired characteristics for trust. This finding aligns with literature on “consucrats” – individuals who themselves are consumers and have become professional advocates, representing a specific group or community. Consucrats often encounter credibility challenges as consumers’ representatives, as they become too professionalized and entrenched in the health system, leading to a loss of effectiveness and authenticity over time (de Leeuw 2020). To ensure their effectiveness and authenticity, broadening their engagement efforts to connect with those they represent is critical. This allows representatives to convey a wide range of real-world concerns beyond their personal views and their efforts gain support from the voices they represent (DeCamp et al. 2021; Yamashita 2013).

Interestingly, our study participants emphasized factors related to input legitimacy (i.e., ensuring fair and inclusive policy making process) over output legitimacy (i.e., producing acceptable policy outcomes) (Boedeltje and Cornips 2004; Strelbel et al. 2019). This could be attributed to the study’s focus on intermediaries’ characteristics connecting more with input rather than output. However, several participants explicitly recognized intermediaries’ constraints in being able to influence policy change while still valuing desired characteristics (e.g., lived experience and shared identity as a LTC resident or a family member or caregiver). This may indicate that participants recognize the legitimacy deficiencies existing within the procedural elements of current LTC policy making environments, while also understanding the dynamics associated with achieving policy change.

Implications for policy and practice

While many intermediaries have represented and advocated for the interests of residents and families, there is a lack of understanding regarding which intermediaries are perceived as legitimate from the perspectives of those they represent. Our findings reveal the perspectives of LTC residents and families on who they believe can and should represent them in policy making, which has direct implications on LTC policy making in Ontario and other jurisdictions with similar LTC arrangements.

Ontario’s *Fixing Long-Term Care Act* (2021) mandates annual consultations between the Minister of Long-Term Care and organizations representing residents’ and family councils. However, it does not specify which organizations should be consulted, raising concerns about representation in the context of the varied intermediaries within the LTC sector – concerns that were emphasized by our study participants. Governments can address these limitations by disclosing the criteria for selecting organizations and regularly updating the list of organizations chosen, based on feedback from LTC residents and families to better reflect their views. In addition to consulting intermediaries, the government can facilitate direct input

from a diverse range of LTC residents and families while considering the resource constraints of intermediaries, which was also highlighted by our study participants. This requires establishing safe channels to protect those who voice concerns and employing accessible and effective engagement methods for diverse populations. By implementing these measures, the government will take important steps toward ensuring legitimacy of their policy making approaches in the eyes of LTC residents and family members. If other jurisdictions similarly recognize the active roles of intermediaries representing LTC residents and families in various PE initiatives, these recommendations could be valuable for government entities in enhancing the legitimacy of their policy making approaches.

Intermediaries in Ontario and other jurisdictions aiming to enhance their legitimacy should regularly engage with LTC residents and families to gather comprehensive first-hand knowledge. Such engagement will demonstrate their commitment to their representative roles. Furthermore, they can develop competencies to be effective in the policy making arena, including advocacy, political entrepreneurship and communication skills. Publishing summaries of their engagements and detailing how engagement input influenced their activities could also foster transparency, an important enabler to increasing perceived legitimacy.

Implications for future research

This study purposefully used a broad definition of intermediaries without differentiating between the various types (e.g., individuals, small-scale organizations, large-scale organizations). Future research could explore how perceptions of legitimacy might vary by the distinct types of intermediaries, as their responsibilities, memberships, organizational structures and resources inherently shape their characteristics and activities. Additionally, with participants prioritizing input legitimacy over output legitimacy, further research can investigate the empirical and perceived connections between the two. Lastly, it is crucial to investigate the perceived legitimacy of intermediaries' representation and desired characteristics across different contexts, considering the necessity of intermediaries for other populations who cannot advocate themselves.

Conclusion

This study has uncovered three essential characteristics of intermediaries closely related to their legitimacy in representing LTC residents and families, as perceived by them. Our findings offer valuable insights for government and non-government organizations endeavouring to enhance or maintain legitimacy within the long-term care policy making process, particularly where intermediaries play an active role.

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