

## **Abstract**

As a family caregiver and an advocate for my mother in long-term care (LTC), this was a personal project for me. It was initially motivated by the prolonged lockdowns of LTC homes which isolated residents in poorly constructed efforts to protect them from Covid-19 (Abbasi, 2020; Frank et al., 2022; Mills, 2021). There is already a wealth of literature and ongoing work adequately exploring multiple aspects of these issues. Copious family caregivers, professional advocates, medical professionals, social workers, researchers, legislators, and many others have been calling urgent attention to the ongoing issues in LTC homes that had been laid bare during the pandemic (Werner et al., 2020). In a sea of family and advocate stories, however, relatively few residents are quoted, referenced, or directly included in the opining on their experiences. Ultimately, this realization led me to explore LTC residents' perspectives about self-advocacy regarding policies that affect them.

## **Introduction**

"Long-term care is a deep, dark hole, and we need to shine a light in there" (CA State LTC Ombudsman, personal communication, 2020). One of the central problems in LTC is the lack of regard for residents' perspectives in policies that affect them (Carlson, 2023; Frank et al., 2022; Levins, 2022; NASEM, 2022). This problem is evident on a micro, mezzo, and macro level. The aim of this project was to gain a better understanding of LTC residents' perspectives regarding self-advocacy in LTC policies, what is hampering it, and what is elevating it.

## **Research Questions**

What are the experience-based perspectives of long-term care (LTC) residents and family caregivers regarding self-advocacy and LTC policies? What do those insights point to as factors contributing to the enablement or disablement of self-advocacy efforts in LTC? What actions can be taken by the community, the public, LTC professionals, policymakers, and fellow advocates to ensure LTC resident voices are empowered, heard, and heeded?

## **Methodology**

There were three parts to this project. First, a scoping review of the literature was conducted to explore the research questions. Second, informal public polls were posted online to determine the applied aspect of the project. Finally, for the applied aspect of the project, interviews were conducted with LTC residents and family-caregivers for a publicly available series of brief videos.

## **Literature Review**

A scoping literature review was performed through academic databases to locate relevant peer-reviewed articles featuring the perspectives of LTC residents regarding advocacy and policies that affect them. Initially, 1728 English-language texts published between 1993 and 2023 from anywhere in the world were screened for relevant content. Finally, 49 peer-reviewed journal articles were included for thematic interpretation of residents' perspectives. Three distinct themes emerged among most resident accounts across the 49 articles that can be perceived as barriers to self-advocacy:

1) **Barrier 1:** A learned sense of worthlessness and invisibility often leads them to relinquish their sense of individual personhood and autonomy. This is often linked to a rushed, regimented schedule built for facility and staff convenience. This culture teaches residents that their individual needs are unimportant. For example, "I'm just a number ...I feel myself worthless here" (Hellstrom & Sarvimaki, 2007, p. 421).

2) **Barrier 2:** There is little to no dignified privacy, consultation, or communication despite residents' right to them. As one resident put it, "We are not little children, we are adults who want to know what is going on" (Boelsma, 2014, p. 50).

3) **Barrier 3:** Fear that speaking up would have negative consequences. Residents are dependent upon staff for support to varying degrees which leaves them in a uniquely vulnerable position. As a result, residents are silenced in fearful reluctance to speak up for themselves or others in the care home: "I won't say anything anymore. Otherwise [nurses] might start hating me" (Bomhoff & Friele, 2017, p. 5).

While less common in the literature, there were some exemplary care homes and LTC care models that empowered residents to advocate for themselves and others. For example, residents were empowered by facility leadership who invited and followed-through on their input, staff members who appreciated and respected them as individuals, and a built-environment that provided them with a dignified private space to call their own (Drageset et al., 2017; Scales et al., 2019; Waters, 2022). Empowered residents also advocated for fellow residents in need (Scales et al., 2019).

There were also instances of community inclusion that offered another avenue for empowerment. For example: "...being part of a co-researcher team was enlightening, and gave us new opportunities to learn, work, and get ideas for our own project advocating for people with

disabilities living in long-term care homes" (Aubrecht et al., 2021, p. 1715)

### **The Polls**

An informal multiple-choice poll was posted in relevant online forums asking people to vote between two choices for the applied aspect of the project: 1) a mini documentary series about LTC resident and family caregiver experiences with advocacy around LTC policies, or 2) a networking app or website to potentially connect LTC resident and family councils across the US. Of 71 unique responses, a majority of 43 votes chose the mini documentary series.

### **Mini-Documentary Series**

Finally, for the purpose of creating the mini-documentary series of videos in the vein of a digital storytelling research methodology, public footage of LTC and family caregiver self-advocacy efforts between 2020 and 2023 were collected and interviews were conducted with four LTC residents and two family caregivers who are known to engage in advocacy efforts. They were recorded in Zoom after informed consent and video releases were obtained. Interviews were semi-structured with broad questions exploring the research questions and related themes found in the literature. Conversations averaged approximately 90 minutes in duration.

With the assistance of a professional video editor, the first of several planned videos was compiled as a resident spotlight. The participant was consulted for feedback and input which was implemented in the final edit. Additional videos are planned for completion and release throughout the remainder of 2023. The series aspires to be an easily digestible educational action tool to be shared with LTC professionals, policymakers, and the public. It also endeavors to serve as an empowering thread of connection, community, and unification for current and future LTC residents and family caregivers.

In many ways, the video interviews echoed the themes found in the literature review. However, for the residents in the video series, clear bridges to self-advocacy were forged in their connections with the greater community. All residents in the interviews had this in some form. For example, "Community was so instrumental... Our community on Roosevelt Island, the art that we were using for our voices... It was a combination... Through our voices and and the community, you know, we were able to to connect to our local politicians..." - Peter, Nursing Home Resident

Meanwhile, the family caregivers were strongly focused on the theme of consequences for their advocacy. One of

the caregivers has two friends in LTC who she coaches toward self-advocacy, but it is sensitive due to the fear of retaliation. The other family caregiver has a brother who is nonverbal and is immobilized in bed. She expressed a constant need for negotiating her advocacy priorities to avoid threats to his safety when she cannot be there with him.

### **Results/Findings:**

One resident sums it up in a 2017 Star Tribune special report, "It's not because we don't have a voice. It's because people in power deliberately choose not to listen" (Serres, 2017, p. 29). The predominant culture in LTC teaches the resident that they no longer matter, must comply, and are powerless to effect change. It's no wonder that most residents do not engage in self-advocacy. The ones who do are empowered by staff, management or community. They are treated with respect and dignity as a person whose opinions matter. If the existing literature is any indication of the overall LTC landscape, then most LTC environments currently fail to foster a culture of equity, respect, dignity, and empowerment. At this time it is rare to see residents with an active voice in policy, much less a dedicated seat at the decision-making table.

### **Conclusion**

Future studies should be focused on activating community involvement and outreach for residents in LTC homes. Ageism and Ableism is an obstacle in the community that must be overcome to get more surrounding communities to flatten the institutional walls between them and LTC residents. Education could be one solution. Utilizing digital storytelling in participatory research that enables residents to express themselves in personally unique ways that engage and enlighten the community is a potential key to unlock hearts and minds to the mutually beneficial collaboration that a few rare trailblazers have already proven is possible.

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