Volunteers' experiences building relationships with long-term care residents who have advanced dementia

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Abstract

Healthcare volunteers make important contributions within healthcare settings, including long-term care. Although some studies conducted in long-term care have shown that volunteers contribute positively to the lives of people living with advanced dementia, others have raised questions about the potential for increasing volunteers' involvement. The purpose of this study is to understand volunteers' perspectives on their work and relationships with long-term care residents with advanced dementia. A total of 16 volunteers participated in semi-structured interviews about their experiences. Interview data were analyzed using an inductive approach to thematic analysis. In this analysis, a central concept, *relationships in dementia care volunteering,* enveloped four related themes: mutuality and *empathy as the foundation for dementia care relationships with residents, family as the focus of volunteer relationships, relationships shaped by grief, and staff support for volunteer relationships.* We conclude that in long-term care settings, volunteer roles and relationship networks are more robust than they are often imagined to be. We recommend that long-term care providers looking to engage volunteers consider training and supporting volunteers to cultivate relationships with residents, family, and staff; navigate experiences of loss; and be considered as members of dementia care teams.

Keywords

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The long-term care sector has been criticized for relying too heavily on a biomedical model of care that does not sufficiently address the significance of relationships among residents, staff, family members, and the community (Sutherland et al., 2019). Recently, this critique has manifested in repeated calls for a more relationship-centered approach, which promotes mutually beneficial relationships between the person in need of care, their family members and friends, and paid care staff (Beach et al., 2006; Rockwell, 2012). Relationship-centered care shifts the emphasis from the healthcare institution to family and community by enhancing communication, promoting an appreciation of the role of family and community in supporting residents, and fostering teamwork (Barken & Lowndes, 2018).

Volunteers play a critical role in promoting a relational approach to care in long-term care settings. In some ways, this is a natural outcropping of volunteers' own motivations, which include working with people, networking, and socializing (Claxton-Oldfield et al., 2005; Tingvold & Førland, 2021). Volunteers typically experience their relationships as very rewarding and associated with positive feelings and increased empathy (Greenwood et al., 2013, 2018). They appreciate the opportunity to help others, meeting their needs, and making a difference in their lives (Claxton-Oldfield & Claxton-Oldfield, 2012). The gratitude expressed by patients and families is personally satisfying to volunteers (Claxton-Oldfield & Claxton-Oldfield, 2012).

The reported outcomes associated with healthcare volunteerism care are consistently positive (Handy & Srinivasan, 2004). In long-term care contexts, over 60% of residents have dementia (Canadian Institute for Health Information, n.d.). These residents continue to benefit from strong relationships, but also become more reliant on others to nurture these relationships (Bramble et al., 2009; Brownie et al., 2014). Within long-term care, residents with dementia demonstrate higher levels of pleasure and interest when they are engaging with volunteers as compared to when they are alone (Hunter et al., 2018). Families express appreciation for the social interaction that volunteers provide for long-term care residents when family members and staff are unavailable (Piechniczek-Buczek et al., 2007). Long-term care staff, who speak of a lack of adequate time as a structural barrier to providing relational care (Barken & Lowndes, 2018), also express appreciation for volunteers' capacity to support residents' social needs (Hunter et al., 2018; Söderhamn et al., 2012). Most studies focus on relationships volunteers maintain with long-term care residents, giving less attention to relationships with family caregivers and staff, despite the multi-directional benefits of involving volunteers in the care of long-term care residents with advanced dementia (e.g., Hande et al., 2021).

Volunteer work with long-term care residents typically includes providing social (Faulkner & Davies, 2005), emotional, and practical support (Macvean et al., 2008). Volunteers develop a mutual sense of friendship with residents (Malmedal et al., 2020), and develop valuable new skills, including skills specific to navigating relationships with people who have dementia (Guerra et al., 2012). However, many long-term care residents have dementia, and some volunteers find cultivating relationships with residents who have dementia to be challenging. For example, volunteers may experience anxiety, perhaps expecting that working with individuals who have dementia will be difficult, and that problems are likely to arise (Damianakis et al., 2007). First-time volunteers may be particularly likely to find themselves feeling less comfortable responding to the needs of residents with dementia (Foong & Zhao, 2016) and that they may benefit from more structure, support, and training (Hunter et al., 2018; Van der Ploeg et al., 2014). Furthermore, support, training, and a clear description of the volunteer role have been identified to be important factors in increasing volunteer retention and satisfaction (Chung, 2009; Hurst et al., 2019; McDonnell et al., 2014).

Beyond building relationships with people who have dementia, volunteers in long-term care settings also often find themselves interacting with family caregivers. Relationships between

volunteers and family caregivers have received very limited attention in research. In the few studies that do describe these relationships, volunteers have been described as having an "in-between" role where they are not quite a friend of the resident, and not quite a staff member either (Weeks et al., 2008). This less defined, in-between role seems to allow volunteers to act as an intermediary between family members and staff when needed by either party, promoting more effective communication and continuity of care (Hande et al., 2021). Current research also suggests that there are reciprocal benefits in the relationships between volunteers and family caregivers. For example, volunteers support families by supplementing psychosocial care (Piechniczek-Buczek et al., 2007). Additionally, volunteers who speak regularly with residents' family members feel positively involved and motivated to be engaged (Guerra et al., 2012).

Working in long-term care also brings volunteers into regular contact with staff members. Although staff are conceivably an important source of support for volunteers, and volunteerism supplements staff work, research on healthcare volunteer experiences (in diverse contexts) suggests that volunteers do not always find it easy to cultivate relationships with staff (Meyer et al., 2018; Netting et al., 2004; Wong Shee et al., 2014). Problems between volunteers and staff are not always voiced openly, yet they may still be present (Rimes et al., 2017). A potential source of strain on relationships between staff and volunteers is the limited amount of time currently allocated to orienting volunteers and staff to each other's work. This can lead to a lack of clarity regarding the roles of volunteers and staff with respect to one another (Tingvold & Skinner, 2019). Role clarification is an important initial step for supporting relationships between staff and volunteers (Hande et al., 2021; Hurst et al., 2019). With adequate role development and support, long-term care staff may be enthusiastic about the contributions of volunteers, recognizing the benefits to residents and to their own work (Hunter, Rissling, et al., 2020; Hurst et al., 2019).

An additional complexity faced by volunteers working in long-term care contexts is that the average length of stay in long-term care is currently as short as 18 months in some countries, meaning that most of the people who move into long-term care are near the end of life (Armstrong, 2018; Sussman et al., 2017). A palliative approach to dementia care is increasingly advised. This approach emphasizes prioritizing psychosocial needs alongside symptom management and considers residents and family members as both care team members as well as the focus of care (Sims-Gould et al., 2010). The need to support families in being more closely connected during this time is also acknowledged (Barken & Lowndes, 2018; Rockwell, 2012). Although dementia is acknowledged as a life-limiting illness (Brodaty et al., 2012), little is known about how volunteers are supported in adapting to these needs as residents with dementia approach the end of life. One intervention, called Namaste Care, has encouraged the cooperation of families and community volunteers in supporting comfort and quality of life in late-stage dementia through a hospice-like day program, with positive outcomes (e.g., Kaasalainen et al., 2020; Simard, 2007; Simard & Volicer, 2010). Concerning outcomes specifically associated with volunteerism, Tasseron-Dries et al. (2021) found that family caregivers involved in a Namaste Care program perceived their involvement with volunteers in the program as positive, and that the program facilitated meaningful contact with their relative. Nevertheless, such approaches seem quite uncommon within the long-term care sector overall, raising questions about how volunteers experience late-stage dementia care.

Given that long-term care is increasingly recognized as an important context for a palliative approach to care (Hunter, McCleary, et al., 2020; Kaasalainen et al., 2019), in this study, our goal was to explore volunteers' experiences working with people who have advanced dementia and are approaching the end of life. Given the significance of relationships between people with dementia, family members, and healthcare staff at the end of life, we approached this question with open attention to all forms of relationship described by volunteers.

Methods

Ethics

This study received ethical approval from the Hamilton Integrated Research Ethics Board (#2865).

Design

This was an explorative qualitative study underpinned by a subjectivist epistemological perspective and a critical realist ontological perspective.

Participants and setting

In 2018, a sample of volunteers was recruited from three purposively sampled healthcare facilities in the province of Ontario, Canada. One of the participating healthcare facilities was a Transitional Care Unit in an acute care setting, and the other two were medium (120 beds) and large (340 beds) not-for profit long-term care homes. Convenience sampling was used to recruit volunteers. To be eligible to participate in this study, volunteers had to be adults (> = 18) with at least 1-year of experience volunteering one-to-one with residents who have advanced dementia.

Data collection

Volunteers were asked to participate in an interview at the health facility where they volunteered. Group interviews were scheduled, and additional individual interviews were scheduled to accommodate those who could not attend. Interviewers explored volunteers' experiences interacting with people with advanced dementia by asking volunteers about how they care for and interact with people with advanced dementia; how they involve family; and how they support staff. Prior to the interviews, participants reviewed information about the study; discussed the study with research staff; and confirmed written consent to participate. Two research staff conducted the interviews and audio-recorded them for transcription purposes. Group interviews were approximately 60 minutes long, while individual interviews lasted 30–60 minutes. A professional transcriptionist transcribed the interviews verbatim.

Data analysis

To assure sensitivity to context, the lead analyst spent 4 months in late 2019 volunteering in long-term care (Yardley, 2000) while other analysts engaged in long-term care research, work, and communities of practice. In 2020, thematic analysis of the interviews began, using the tradition of Braun and Clarke (2013) (see Figure 1). Thematic analysis can be adapted to diverse ontologies and epistemologies. The individual ontological perspectives of members of this research team individually varied along the spectrum of critical realism to relativism, and our analysis reflects this. From time to time, we leaned into the more relativist assumption that the experiences and meanings described in our research are rooted in social discourse (recognizing the research process itself as a form of discourse). In doing so, we gave ourselves the freedom to draw from our own immersion in the long-term care context as we interpreted findings, and in this sense, co-constructed meaning with our participants. Nevertheless, as clinical researchers, we ultimately found ourselves pulled back toward the realist end of the interpretive spectrum by our common interest in identifying what would
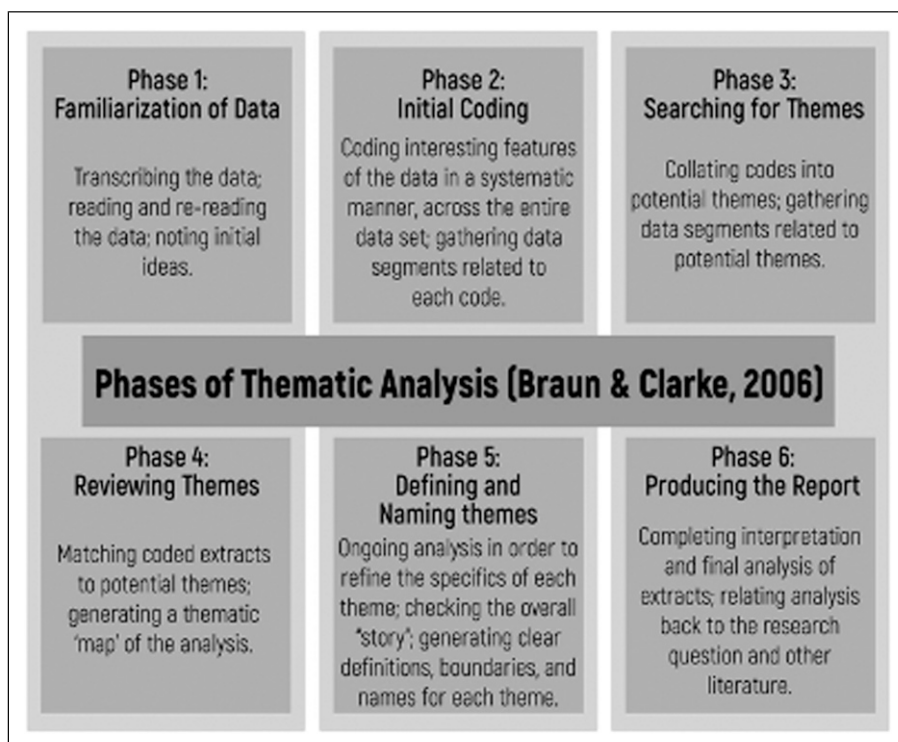
Figure 1. Graphical representation of phases of thematic analysis.

ultimately improve the experience of people living, working, and volunteering in long-term care. Our analysis was *inductive*; that is, we did not rely on a particular theoretical frame to analyze the interviews, preferring to focus instead on our own interpretation (Braun & Clarke, 2006; Elo & Kyngäs, 2008). At the outset, we attended most to *semantic (manifest) content*, considering the main topics the participants spoke about, and relying on the words participants themselves used (Braun & Clarke, 2006; Graneheim & Lundman, 2004). Yet, as our analysis proceeded, and we began to discuss the implications of the findings as a team, attention to *latent content* (i.e., implied meaning of and associations among themes) influenced the process of naming the themes, prioritizing some over others, and organizing the themes in relation to each other (Braun & Clarke, 2006, 2019; Madill et al., 2000). This was the point at which we initially felt most timid, as we departed from qualitative research "recipes" toward more active interpretation, heeding prior "black box warnings" about recipe-based analysis (Braun & Clarke, 2019; Sandelowski, 2010). As we allowed ourselves to be guided by our own immersion in the long-term care context, we began to feel more confident that we were presenting a truer picture of volunteers' meanings.

Using Braun and Clarke's (2013) approach to thematic analysis, the lead analyst first read and reread the transcripts, making notes regarding initial interpretations. Second, the data was coded and third, codes were collated into themes. These were reviewed by the third author, with reference to the original data. This led to additional collapsing of codes within the themes and renaming of themes. Next, all coded extracts were matched to potential themes, creating a thematic "map" of the analysis. Subsequently, through discussion among all authors, some themes were renamed to achieve greater

coherence and consensus, and to better communicate the significance of the findings (Elliott et al., 1999; Yardley, 2000). During this process, one theme aligned poorly with the others, whereas a subtheme within it aligned closely. To achieve greater coherence, the subtheme was emphasized and the major theme dropped (cf., Madill et al., 2000). In the final step, themes were described in rich detail alongside quotations from participants.

Findings

Three group interviews (Site 1, N = 6; Site 2, N = 4; Site 3, N = 3) and three individual interviews (all at Site 1, to accommodate people who could not join the group interview) were conducted with active volunteers, who agreed to share their experiences working with residents who have advanced dementia (total N = 16 across 3 sites). Most participants were female (N = 13); the remainder, male (N = 3). A majority (68%) of the participants were 65 years or older. Four (25%) were under 25 years old, and one (6%) was in the 55-to-64-year age bracket. On average, volunteers had 2.69 years of experience in long-term care (range 2–5 years; SD = 1.03 years).

Four key themes represent our analysis of volunteers' experiences working with long-term care residents who have advanced dementia. These themes are: *mutuality and empathy as the foundation of relationships with residents, family as the focus of volunteer relationships, staff support for volunteer relationships, and lastly, relationships shaped by grief* (see Figure 2). These themes are encompassed within an over-arching theme of *relationships in dementia care volunteering*.

Mutuality and empathy as the foundation of relationships with residents

Most volunteers spoke to how positive and rewarding volunteering can be, suggesting that their relationships with residents were considered mutually beneficial. They also described growing in empathy as they formed relationships with residents who have dementia.

Mutuality in dementia care relationships. Volunteers perceived their work with people living with dementia as rewarding, and this perception seemed to motivate them to continue their work. For instance, volunteers were often gratified when they received feedback that their work was making a difference, whether from others or from their own observations about the resident's response to their work, as expressed in the following statement:

> It's also rewarding in the sense of seeing some of the residents as they… well they don't progress but progress in their own way … it's quite an experience for myself. (Participant 2, Group Interview, Site 1)

Simply being present with the residents and knowing that this *might* be received as a source of support or comfort was enough reward for other volunteers. Still others spoke of the opportunity to learn about dementia as one of the rewards of their work.

Volunteers often spoke about their enjoyment of social interactions as an additional motivation, or benefit. When residents were able to communicate orally, volunteers enjoyed learning from these social exchanges. As one volunteer described, "I would go in and I would start talking with them. They would talk about their histories, and it was just really meaningful" (Participant 10, Individual Interview, Site 3). When residents communicated primarily through non-verbal expressions, volunteers spoke of adapting to rely more on non-verbal cues to support their social connections. For example, one volunteer commented on the way that being recognized and greeted with a smile
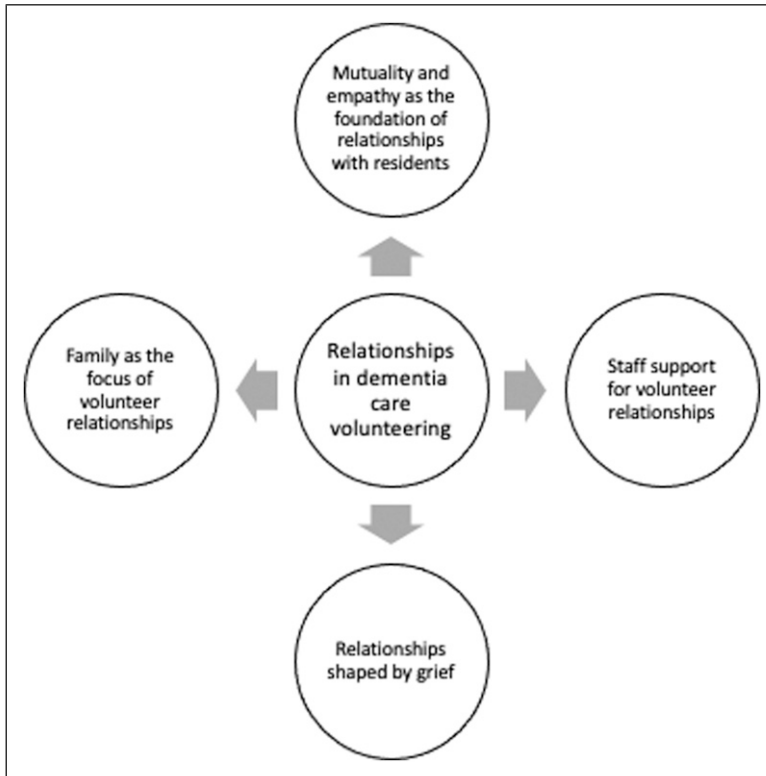
Figure 2. Graphical representation of volunteers' experiences with dementia.

reinforced their social connection: "I find it very rewarding. …. Because when they come down, they smile. What more can you ask for?" (Participant 4, Group Interview, Site 1).

Empathy in dementia care relationships. It was initially challenging for volunteers to spend time with residents who exhibited limited communication skills or unanticipated inconsistencies in mood and behavior. However, as volunteers gained more experience of dementia care, they found that empathy grew in three main ways: they developed a better understanding of the symptoms of dementia, leading to more tolerance and flexibility; they resisted dementia as a defining characteristic of a resident's identity; and they allowed their evolving understanding of the person living with dementia to guide their approach to volunteering.

Empathy for long-term care residents living with dementia increased as volunteers acquired more knowledge of dementia through their day-to-day experiences with residents. Knowledge about dementia seemed to increase through implicit learning. For example, one participant confessed that they were uncomfortable supporting residents' memory failures at the beginning but gradually, over the years, became more comfortable answering the same question several times during a conversation, and gained skill at relying on non-verbal cues (Participant 5, Group Interview, Site 1). Increased experience with dementia helped volunteers to contextualize the mood and behavior changes residents sometimes experienced. For example, one volunteer described, "It's [often] very easy and they are very comfortable, but they can turn very quickly" (Participant 1, Group Interview, Site 2). Being better able to contextualize

these changes helped volunteers to avoid taking these reactions personally, and to take a lead role in maintaining and improving relationships. Overall, they learned to take the good days along with the bad, exhibiting greater tolerance and flexibility in their relationships with residents.

Volunteers also began to understand that although dementia is part of someone's life, it does not completely define them. They started to perceive dementia more as a mental illness, health condition, or disability, as opposed to a fundamental change in personhood:

> "Because you know it made me realize that dementia doesn't define somebody; it's just something the person has. Like, it's a mental illness, but that doesn't define who they are" (Participant 10, Individual Interview, Site 3).

As they began to resist the idea that dementia defines identity, they invested in learning more about the residents' life histories. As they came to appreciate the residents they were working with more fully, and drew more parallels with their own lives, they also began to place themselves in the residents' shoes: "One day it will happen to you. So never say that [it won't]. Because they are human beings like everyone else. And 1 day, who knows" (Participant 4, Group Interview, Site 1). Imagining dementia as a possible future outcome seemed to help volunteers avoid approaching residents as an outgroup, and instead approach them as part of a group that they might belong to at some point. This helped them to treat residents the way they would wish to be treated if their own cognitive health was to change.

Finally, volunteers also expressed empathy by allowing their new understanding to shape their responses to people with dementia. For example, one volunteer observed that residents with advanced dementia benefit from a different level or kind of engagement:

> I think that engagement when you have advanced dementia also looks different right? Like engagement doesn't have to mean that you're playing basketball with other people. It could mean that you're just in that environment and like observing or like being involved in what's going on. So engagement could just be like being in a comfortable relaxing space… that is relaxing them…. (Participant 3, Group Interview, Site 2)

Additionally, cognitive impairment associated with dementia can result in the expression of false beliefs or misperceptions of current events, and volunteers quickly learned that emphasizing facts could be more harmful than beneficial. Volunteers often described going along with a story to avoid upsetting the resident. As one volunteer put it, "The person would say something that, it wasn't true... I go along with it" (Participant 3, Group Interview, Site 1).

Overall, empathy was cultivated by learning about the disease and the person, and by imagining oneself as a person who might 1 day be vulnerable to the same disease. Empathy was an important foundation for volunteers' relationships, and guided their approaches to dementia care.

Family as the focus of volunteer relationships

Interacting with families was an important focus of volunteer work in long-term care. Volunteers' roles included building relationships with family members, learning more about residents through families, and acting as a surrogate for familial rituals contributing to residents' well-being, when family members were unavailable.

Volunteers perceived family members as an invaluable resource to learn more about residents. Families helped to inform volunteers about residents' needs, furthering their understanding about residents' lives before coming to long-term care. One volunteer described that learning by observing

families can be just as important as learning by conversing with families: "Watching the family or talking to the family is a really good way to build an understanding of the best way to interact with residents" (Participant 3, Group Interview, Site 2).

Volunteers also mentioned that they were more likely to engage with family members when a resident was in the later stages of dementia. At this time, volunteers were often less involved in engaging the person with dementia directly, and their focus shifted to supporting and engaging with the family:

> I think we really get to know the families. (…) Because we're here regularly and the family members are here almost every day. And you know, oftentimes in the advanced state of dementia, like the [resident] is in … bed and not responsive and … that's where the volunteers really connect with the family. (Participant 1, Group Interview, Site 3)

During the course of their work, volunteers learned that there was diversity in family availability and engagement. When family members were unavailable, volunteers often took it upon themselves to provide supplemental care and attention:

> It is just interesting to see the dynamics that a family has and whether residents have huge families supporting them or just a small number of family members. Some residents do not have those relationships or do not have those family members coming in to visit. That can kind of help you target who needs the support more, and who is getting the support from family and who is not (Participant 3, Group Interview, Site 2).

Additionally, some volunteers spoke to the significance of holidays and special days such as birthdays, and believed that families appreciated it when they mitigated the resident's need for companionship when family members could not be available: "It's nice to know that somebody is always looking out for a loved one. So that kind of support is appreciated I guess" (Participant, Individual Interview #1).

Staff support for volunteer relationships

Volunteers recognized that forming strong relationships with people with dementia requires unique knowledge and skills, and that they relied heavily on their relationships with staff to improve their skills. Strong relationships with staff helped volunteers negotiate challenges that arose in their work.

Volunteers' comments suggested that they felt supported when staff helped volunteers when care needs went beyond their scope or abilities. For example, one volunteer noted, "We're not allowed to touch, we're not allowed to pull people's pants up (…) or you know do any of that physical care, because that's nursing" (Participant 1, Group Interview, Site 3). Volunteers also perceived staff members' readiness to provide information and respond to questions as an important form of support; for instance:

> So they will be calling to get somebody to help go to the washroom. And that would be a very uncomfortable feeling if you actually have to go to the bathroom and nobody is helping you. But the staff will know [and say], 'oh they just went to the washroom ten minutes ago [and] they haven't had any [additional] liquids.' (Participant 3, Group Interview, Site 2)

Volunteers expressed appreciation that even when staff did not know them well, they appeared to notice volunteer presence and were ready to assist. Volunteers felt responsible for unmet needs of

long-term care residents, and when these pressures were recognized through direct assistance or reminders that staff were there to help, participants felt supported, and their sense of pressure was eased: "There's no pressure there, they're always asking me not to over burden myself" (Participant 3, Group Interview, Site 3). Overall, volunteers appreciated practical and informational assistance, information about role boundaries, and direct expressions of support.

Volunteers also noted that they were sometimes called upon reciprocally when staff needed support, confirming to them that there was a team relationship between staff and volunteers. They felt particularly supported and appreciated when staff recognized them as part of the team providing care to residents with dementia:

> I feel that we're really part of the team here. Because it's a big team here on Behaviour Health and I know how important the volunteers are, because the needs are so high for the patients (…) So I feel like our contribution is really highly valued. And I think we've been given a good position on the team and I think we get a lot of recognition and we get a lot of thanks (Participant 1, Group Interview, site 3).

Expressions of care and concern for volunteers' experiences contributed to a sense of teamwork. Volunteers highly valued being recognized as members of the care team.

Relationships shaped by grief

It was not unusual for long-term care volunteers to experience bereavement during the course of their work with long-term care residents living with dementia. They spoke of their preparedness for death, the experience of bereavement, and their involvement in end of life and bereavement rituals.

Among volunteers, there was an implicit expectation that they must be prepared for the deaths of the residents they worked with. Volunteers did not need to be told to prepare for this possibility; in contrast, they recognized that some of those they were working with were near the end of life, and with experience, they developed coping mechanisms to adjust to repeated loss. One coping mechanism was anticipating loss. For some, anticipating loss seemed to facilitate a certain kind of detachment, or perhaps acceptance, which was perceived to help modulate grief at a resident's death:

> When I first started here and somebody passed away, I went home very upset. But now I've got to the point that I know what's going to happen so I can…not detach itself but kind of…not let it get to you."
> (Participant 2, Group Interview, Site 3)

Other volunteers maintained their attachment, or emotional bond, with residents who were dying, and recognized their grief as proportional to the strength of the relationship or the frequency of contact:

> And it also makes it difficult when I'll engage with the patient one on one almost every week and then I would come back and hear that they've passed away or something. That also makes it I guess more uncomfortable for me. Because I've started to you know bond with that person and now, they're gone (Participant 10, Individual Interview, Site 3.

Despite volunteers' implicit understanding that many long-term care residents are nearing the end of life, a failure to recognize the impact of bereavement on volunteers reduced the quality of the volunteer experience. For instance, in the previous example, it was taken for granted that the volunteer would be notified of the death on their next workday, yet this was awkward for the

volunteer. Additionally, some volunteers noted that they were invited to participate in death rituals, including funerals, bedside vigils, or other services, but felt it would be helpful to have more guidance and support for fulfilling this role:

> Well one thing, they've got to get sensitivity training because I have been at bedside vigil because there's no family member available. So you're there, you don't know whether you're effective or not but you're there (…) But it's a hard place for a person to come (Participant 3, Group Interview, Site 3).

On the other hand, some volunteers described opportunities to attend memorial services with the resident's family and community and conveyed that this was highly meaningful. For example, in describing a service for a deceased resident, one volunteer said:

> And we do attend, and the family are happy that we're there …. It was really a lovely ceremony, and everyone got to talk about that person and what they loved about her. So that was really positive and it was helpful …. And I'm glad as volunteers we're invited to go to those services…. And the families are happy to see us there too, because I think you know they feel like their loved one was well loved by everybody" (Participant 1, Group Interview, Site 3).

The time of a resident's death was perceived as a key time for the resident's care team (including family, volunteers, and staff) to mourn the loss and to support each other.

Overall, several interviewees had experienced bereavement in their volunteer roles and, shared that with experience, they learned to adjust. Yet, they felt additional consideration could be given to their roles and relationships with dying residents, their families, and the staff involved in supporting their care. This was perceived as a way to support them and to improve the quality of their work.

Discussion

The purpose of the current study was to understand volunteers' experiences working with people who have advanced dementia and are approaching the end of life, with particular attention to the way they described their relationships. Using an inductive approach to thematic analysis, these experiences were represented as four key themes encompassed within an over-arching theme of *relationships in dementia care volunteering*. These included: *mutuality and empathy as the foundation of relationships with residents, family as the focus of volunteer relationships, staff support for volunteer relationships, and lastly, relationships shaped by grief*. By studying volunteers' experiences with residents who have advanced dementia, this study sheds light on topics that have not been studied much to date, including volunteers' provision of family-oriented care, their sense of being a part of the care team, and their responses to death. In addition, this study continued to explore topics often discussed in other studies of volunteerism, including the cultivation of relationships and empathy, and the rewards of volunteerism.

Volunteers felt more efficacious in their work, and more supported by staff when they were treated as part of the care team. Previous research has shown that volunteers consider staff support and volunteer training to be important (Hunter, Rissling, et al., 2020; McDonnell et al., 2014). Additionally, support and training have been found to be associated with reduced emotional distress, potential burnout, and dropout rates among volunteers (Chung, 2009; Hurst et al., 2019). However, the direct incorporation of volunteers into care teams has not been widely studied. One study using multi-level path analysis to examine volunteers' perceptions of inclusion in healthcare teams showed that, when volunteers felt included, they felt self-efficacious and more connected to others (Bidee

et al., 2017). Given these positive outcomes, it may be important for long-term care facilities to guide and mentor their care teams toward thinking of volunteers as part of the care team. Recognizing volunteers as members of the care team is consistent with a relationship-centered philosophy. This tradition rests on mutual recognition, and response to the needs of each other; encompassing residents, family members, volunteers, and staff (Wilson et al., 2009). Ultimately, such an approach is best fostered by making the cultivation of strong relationships a priority for the whole organization (Wilson, 2009).

Within the long-term care sector, volunteer experiences with bereavement are poorly researched. Yet, this topic has been pursued in other sectors. For instance, Claxton-Oldfield (2014) found that hospice care volunteers develop a greater acceptance of death. This is consistent with findings of the current study. For example, volunteers reported making adjustments after their initial experiences of loss, and this seemed to promote their capacity to accept and cope with loss. Given that bereavement is a common experience for long-term care volunteers, volunteers would benefit from a relationship-centered approach that includes prompt notification of death, guidance in providing support for dying residents and their families, acknowledgment of loss, and inclusion in funeral ceremonies or related rituals. Further pilot studies and experimental trials of volunteer training models, including those based on a palliative approach to care, would help to expand on these few observations.

Approximately 76% of family caregivers visit long-term care homes at least once per week, while others are less frequently involved (Tornatore & Grant, 2002). Family members are often involved in a range of caregiving activities, including monitoring and managing care, assisting with meals and personal care tasks, and providing emotional care (Gaugler, 2005). Given the stress that family caregivers face (Cohen et al., 2014; Papastavrou et al., 2007), they can benefit directly from the social and emotional support provided by volunteers (Smith et al., 2018). In this study, volunteers clearly conceptualized their role as one that supported both the resident and the family. Volunteers learned about residents' histories and current needs through families, suggesting a significant role for families in training volunteers. When family members were absent, volunteers actively considered how they could supplement some forms of support that are traditionally provided by families, such as being present at personally or culturally significant times. Moreover, the nature of volunteer relationships with residents' family members changed as dementia progressed and ultimately, when residents died. Additional exploration of these relationships would be a valuable new research direction. This could impact training and support for volunteers, which currently does not always address volunteers' relationships with families.

Finally, volunteers grew in empathy and understanding as they spent time with residents, cultivating the foundations of good relationships. Empathy is generally defined as the capacity to understand the perspective of another individual, and it is recognized as an important foundation for person-centered and relationship-centered care (Beach et al., 2006; Brooker & Latham, 2016; Fazio et al., 2018). Morse's (1992) model of therapeutic empathy suggests that empathy is comprised of four components: moral empathy (i.e., intrinsic motivation to practice empathy), emotional empathy (i.e., subjectively experiencing another person's emotions), cognitive empathy (i.e., objectively understanding another person's perspective), and behavioral empathy (i.e., communicating understanding of another person's perspective through actions). Practicing therapeutic empathy can improve relationships with patients (Morse et al., 1992). Our findings align well with this model in that, as volunteers spent more time with the residents, they were able to better understand the experience of dementia, adjusting their interactional style to match this new understanding. For example, as volunteers gained insight into how dementia impacts mood and behavior (i.e., cognitive empathy), they became more tolerant and flexible in their interactions with the residents (i.e., behavioral empathy). Additionally, as the amount of time volunteers spent with residents increased,

so did their motivation to understand the residents (i.e., moral empathy). As a result, volunteers invested more time learning about the lives of the residents outside of their dementia diagnosis. Furthermore, volunteers also began to consider what it would feel like to be the person with dementia (i.e., emotional empathy). As volunteers learned more about the perspectives and experiences of the residents, they adjusted their style of interaction to align with the preferences of each resident, thus enhancing the quality of the relationships. Given the importance of empathy to relationships in healthcare settings, additional exploration of ways to support the development of empathy among staff and volunteers would be a valuable direction for future research.

Although our method did not allow us to examine the role of age in empathy, we did notice that several of the volunteers who participated this study were middle aged and older. One older volunteer gave voice to the thought that she might be a resident 1 day. Research does suggest that capacity for perspective-taking and emotional integration (qualities related to empathy) increase over the lifespan (Commons & Ross, 2008; Kallio, 2011; Sinnott, 1998). Research also documents a decrease in existential anxiety with age (Amjad, 2014) as people acquire more experience with life-limiting illnesses, including dementia. These findings fall within the domain of terror management theory, and they raise the possibility that younger volunteers and people with limited experience of dementia might, on average, find it more emotionally challenging to learn to volunteer in a long-term care context, as some studies of volunteers do suggest (Damianakis et al., 2007; Foong & Zhao, 2016). Nevertheless, since some younger volunteers do seem to adapt and thrive in dementia care settings, it would be valuable to further explore the personal and organizational qualities that help to support this adaptation.

Findings from the current study highlight the importance of training volunteers in how to fulfill their role as part of the care team through the development of relationships with staff, residents, and families. A relational approach to training volunteers has not yet been adequately researched. However, a *Volunteer Unit Model* that incorporates the use of relationships in integrating volunteers into the care team has been implemented in several long-term care homes in Ontario (Health Standards Organization, 2017). In this model, each volunteer is assigned to one unit within the home to promote familiarity and relationships among volunteers, residents, and staff on that unit. New volunteers begin by introducing themselves to each resident and their family members (when possible), and by asking about any specific requests the volunteer can assist with. Continued communication among staff, families, and volunteers is facilitated by resident "guest books" where volunteers record the content of their visits for families and staff to review; and a "communication corner" where information about residents is kept, and staff list special requests for volunteers. Satisfaction survey results indicate that 93% of volunteers were satisfied with this model of integration as it made volunteers feel useful, part of the team, and as though their actions had a direct impact on residents and families (Health Standards Organization, 2017).

Furthermore, research examining the effectiveness of formalized mentorship programs in facilitating the integration of new staff members has shown promising results, including higher staff retention rates (Hegeman et al., 2007) and increased confidence in palliative care delivery (Frey et al., 2020). Although current mentorship programs support staff by cultivating strong relationships, one can easily imagine extensions to volunteers. On a broader scale, relationships in long-term care could also be cultivated through an emphasis on compassionate communities, which emphasize the role of the community in helping to provide care to older adults. For example, in one approach to compassionate communities, residents in hospice care provided university or college students with education on loss and transition by sharing their life stories. Students gained knowledge of death and dying, and created meaningful relationships with residents (Hartley, 2012; Kellehear, 2013). One can easily imagine volunteers receiving similar training. Overall, new models of training that

incorporate mentorship of volunteers and facilitate the development of relationships between volunteers, residents, and family members could be very effective in supporting volunteers as part of the care team in long-term care. Researchers could help to encourage this shift by specifically inquiring about volunteer training and support in studies of volunteer experiences.

Limitations

This study is not without limitations. First, a convenience sampling approach was used to organize group interviews, which were sometimes small or needed to be replaced by individual interviews. Although this approach likely enhanced the voices of individual participants, the study benefits less from the dialog among group members. Second, the research question was framed broadly to facilitate an environmental scan and to permit an inductive analysis, yet explicitly mentioned some topics that were ultimately distinct enough to later be defined as major themes, such as interactions with family. In contrast, some rich content areas, such as the theme of experience with death, were not guided by questions, but would be useful to explore in greater depth with participants who have experience working with dying residents.

Conclusion

In a relational approach to care, residents, families, and members of the community all have a valued role in the long-term care team. Findings from this study indicate that with support and appreciation from staff and family members, some community volunteers were able to experience themselves as members of the care team, and this facilitated their work. By examining volunteers' experiences with residents who have advanced dementia, this study extends previous research findings and suggests the need for further study of topics including volunteer support and role preparation, volunteer preparedness for death, volunteers' interactions with families, and incorporation of volunteers into care teams. Continued work to understand and support volunteers may be one way to further delineate the networks of relationships within long-term care and enhance capacity by cultivating community.

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