## ORIGINAL ARTICLES

# "They don't just disappear": Acknowledging death in the long-term care setting

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## ABSTRACT

*Objective:* The purpose of this study was to describe the value of a formal room blessing ritual held within a long-term care facility, from the perspectives of staff, residents, and family members.

*Method:* A qualitative research study involving interviews with staff, residents, and family members was conducted to examine the perceived value of a room blessing ritual.

*Results:* Twenty-four room blessing attendees participated in the study (nine staff, eight residents, and seven family members). Attendees felt that the room blessing provided an opportunity to formally acknowledge the death of the resident and their grief; the majority felt that this was a positive experience and that it provided an element of closure. Staff members and residents expressed their appreciation for the opportunity to connect with family members of the deceased to express their condolences during the ritual. Participants also identified the inclusivity of the ritual (i.e., an open invitation to all staff, residents, and family members) as a positive aspect that served as a reminder that others shared in their grief. Staff members felt that blessing the room for the new resident was an important component of the ritual, helping to bridge the gap between mourning and welcoming a new person. Staff, residents, and family members felt that the room blessing positively reflected the mission and values of the facility. The most highly valued aspect of the ritual for all attendees was the sharing of stories about the deceased to celebrate that person's life.

*Significance of results:* Long-term care facilities need to recognize that formal supports to manage the bereavement needs of staff and residents, such as a room blessing ritual, should be incorporated into their model for managing end-of-life care, given the relationship between the emotional health of staff and the quality of care provided for residents.

**KEYWORDS:** Long-term care, Acknowledging death, Staff bereavement, Ritual

## INTRODUCTION

Death is experienced frequently in the long-term care (LTC) setting (Hanson & Henderson, 2000) and is considered the final outcome for most admissions; therefore, LTC is fundamentally palliative care (Forbes, 2001). It is important to consider the effects that frequent deaths have on staff and residents who live and work in LTC. Compared with other healthcare sectors, uniquely close and significant relationships develop between LTC staff and the residents they care for. These relationships are built through the provision of intimate care over long periods of time, and often include daily contact with residents' families and friends. Although many LTC staff find care of the dying a meaningful and

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rewarding experience (Burack & Chichin, 2001), the extended length of stay and the intimate nature of care provided intensify the grief that is felt by staff when a resident dies.

Staff report a wide variety of grief-related symptoms following the death of a resident: conflicting emotions of both sadness and joy (Tupper, 1996; Touhy et al., 2005); feelings of helplessness, remorse, moral distress, and chronic and compounded grief; feelings of overwhelming stress and burnout (Tupper, 1996; Burack & Chichin, 2001; Anderson, 2008); and a variety of physical symptoms, such as exhaustion, loss of appetite, headaches, nausea, crying, and inability to rest (Tupper, 1996). Little training is provided on how to prevent and address problematic or chronic grief (Anderson, 2008).

Individuals who deal with death frequently, as part of their work or otherwise, must find ways to make sense of dying and death (Moss et al., 2003). In most hospice and palliative care settings, well-trained staff and comprehensive bereavement support are accepted as critical (Touhy et al., 2005); unfortunately, in the LTC environment, staff have perceived that facility administration view care for the dying in functional terms only as just another task (Forbes, 2001) or as "part of the job" (Burack & Chichin, 2001, p. 301). Additionally, death of the elderly is not always recognized as "loss" and may be rationalized as timely and fair because of their frailty and multiple health problems.

When grief is not openly acknowledged or socially supported, it has been referred to as "disenfranchised grief" (Doka, 1989, p. 4). In LTC, the topic of death is often avoided (Sumaya-Smith, 1995; Tupper, 1996; Anderson & Gaugler, 2007) and ongoing work patterns preclude staff from taking time to grieve (Moss et al., 2003; Anderson, 2008). Even less recognized is the grief experienced by residents in the facility who have lived side-by-side with the deceased (Brazil et al., 2004). These factors serve to disenfranchise the grief experiences of both staff and residents and can result in job dissatisfaction and high staff turnover (Van-Hein Wallace, 2009) as well as reduced quality of future resident care (Sikma, 2006).

In the broader community, bereavement rituals, such as funerals and memorial services, provide opportunities to express grief and share a sense of loss. These rituals are usually conducted off the premises of the LTC facility; therefore, staff and residents are often unable to attend. Without formal support mechanisms, staff frequently rely on several sources of informal support, such as turning to coworkers, family, friends, and religious and spiritual groups (Tupper, 1996; Rickerson et al., 2005; Touhy et al., 2005) to cope with the death of residents.

Previous studies identified some strategies to address gaps in formal bereavement support for staff and residents in LTC facilities: postmortem conferences to vent emotions, brief bedside memorials, attendance at funerals and memorial services, leaving the bed empty for 24 hours, announcing the death in the facility in some way, displaying photographs or other mementos of the resident, and expressing condolences to the family (Tupper, 1996; Burack, & Chichin, 2001; Rickerson et al., 2005; Touhy et al., 2005). A common theme is the provision of formalized time and space for staff to gather and share their feelings with other staff members and/or residents (Sumaya-Smith, 1995; Tupper, 1996; Touhy et al., 2005; Van-Hein Wallace, 2009).

Following the death of a resident, a room blessing ritual is practiced at St. Joseph's Health Centre Guelph (SJHCG), an LTC facility in Ontario, Canada. The ritual is led by spiritual and religious care staff and held in the deceased resident's room. Prayers are said and memories are shared in honor of the deceased. The ritual concludes with prayers for the incoming resident and includes leaving a note and token to welcome the new resident. The primary purpose of the ritual is to provide an opportunity for staff and residents to grieve and feel supported in their grief. The room blessing also encourages a more mindful or intentional welcome of the new resident to be admitted to the room.

The purpose of the present study is to describe the value of the room blessing ritual from the perspectives of staff, residents, and families who have attended room blessings in the facility. The findings can provide valuable information to identify formal supports for bereavement and to develop models for managing end-of-life care that address the needs and promote the emotional health of all care team members as well as residents and family members.

## METHOD

### Study Design and Participants

A qualitative research study involving in-person interviews with staff, residents, and family members was conducted to ascertain the value of the room blessing ritual. Ethics approval for the study was obtained from St. Joseph's Healthcare, Hamilton, Ontario, Canada.

Spiritual and religious care staff responsible for facilitating the room blessings compiled lists of room blessing attendees over a 6-month period. Purposive sampling was used to select participants who could communicate proficiently in English; were cognitively able to provide consent to be interviewed and to fully express their views regarding their room

blessing experience; and, in the case of family members, had a loved one who had died more than 3 weeks prior.

Over a 2-month period in 2009, an interviewer contacted eligible participants to request an in-person interview. Selection of participants from each group continued until the interviewer felt that saturation in ideas had been reached.

Nine staff, eight residents, and seven family members participated in the one-on-one interviews. All participants provided written informed consent prior to participating in the interview. The interviewer used a semi-structured interview guide that was slightly modified to reflect each participant group. Participants were asked about the value of the room blessing in terms of overall impression, personal importance, needs served, other available supports, and areas for improvement. Interviews lasted from 30 to 60 minutes.

### Data Analysis

Audio recordings of each interview were transcribed to create verbatim written accounts. To preserve participant confidentiality and anonymity, all identifying information captured on the recording was removed from the transcripts.

Prior to formal coding, two researchers read each transcript independently to gain a sense of the room blessing experience. Qualitative content analysis was applied to identify main ideas and themes within and across participant groups. The process continued until all categories and themes were identified and agreed upon by the researchers. Themes were verified by returning to the original data and were then extracted from the summaries and clustered with similar themes. To support the interpretations drawn from the interviews, direct quotes that were reflective of typical statements made by participants were included in the text. Sources of these quotations were identified using a letter to represent staff (S), residents (R), and family members (F). Some of these quotes were edited minimally to preserve authenticity, while ensuring readability.

### RESULTS

Room blessings served a number of needs, which crossed all three participant groups. Six major themes were identified. The room blessing ritual provided opportunities to: take time to acknowledge death; reflect on and celebrate the life lived through sharing of stories; connect with and express condolences to family members; come together as a community recognizing and including all members of the care team (staff, families, and residents); welcome the incoming resident; and contribute to the overall impression of the LTC facility as an organization that lives its mission and values by providing compassionate care. Participants also identified challenges involved in conducting the room blessing ritual. Each theme will be described in turn.

### Taking Time to Acknowledge Death

Using the room blessing ritual as an opportunity to say goodbye to the deceased and their families was important for staff and residents. This opportunity was viewed very positively. "It's not a chore to go. It's a joy to be able to attend and it's a very satisfying feeling when you are finished" [S6]. The ability to pause for a moment to reflect on the deceased both validated their grief and provided an element of closure. "Working in a place like this you almost become hardened to death because you see it so often and it's important even if it is just for 15 minutes to remember who the person was and that there is another person coming in" [S7].

The aspect of saying goodbye held an additional element of importance for staff who did not work on the "front-line." As one staff member said, "I do feel [room blessings] offer some degree of closure, especially if you are not necessarily a front-line person – you may not have been present in some of those last hours where you are getting closure by helping the family and by being with the client" [S3]. This closure was even more important when a resident died unexpectedly: "The ones that are most important is if somebody dies suddenly. I think the ones that are most helpful are where you do feel that sudden loss and just catches you off guard" [S5].

For residents and families, this moment of reflection was reassuring because it represented an acknowledgement of the death of a person with value who was cared for and about by others in the facility. The theme of "not just disappearing" was mentioned by a number of residents, staff, and family members. One resident said, "It's nice to know that you don't just disappear as though you have never been" [R5]. A family member echoed this same sentiment: "Closure – a nice sort of ending. I'm not sure it's right just to disappear – I value it for that, it was closure that we badly needed" [F6].

### Reflecting On and Celebrating the Life Lived Through Sharing of Stories

A key element of the room blessing ritual highly valued by residents, staff, and families alike was the sharing of reflections and stories about the deceased. When family members were asked what they most valued about the room blessing ritual, the majority talked about how uplifting it was to hear stories

about their loved one. These stories reassured families that staff and other residents felt affection and cared for their loved one. One resident shared, "You know, there was an atmosphere kind of fun sometimes because her mother was a scream. Her mother wasn't supposed to eat donuts and evidently she would sneak in with them and put them down her bra. So, these things came up when we were talking about her, her mother was a rascal. She was wonderful courageous too. It gives you courage to go on. It's a kind of ripple effect you see – I think it kind of ripples through the building … she was one of my favourite people" [R7]. Staff and residents appreciated the opportunity to share their memories and hear new reflections from others. As one staff member stated, "Stories are shared at the room blessings that haven't been shared during the chaos of care" [S3]. The storytelling aspect of the room blessing ritual frequently served to turn an otherwise sad event into a moment of healing laughter, which was often described as "fun" or "comic." "You know, we always laugh. We do more laughing than crying at those, so I think for family and for all of us it's a good thing" [R7]. Similarly, one family member commented: "By no means a sombre event, just sort of reflecting; a lot of good laughs and stories" [F6].

### Connecting with and Expressing Condolences to Family Members

Although family members are not always able to attend the room blessing held for their loved one, their presence is appreciated by residents and staff who most often cannot attend visitations and funerals to offer their condolences to the family. "Often it is nice if the family is there because often I am not able to make it out to the funeral or visitation so it's that opportunity to have closure in that relationship as well; I really appreciate it when the family is able to be there, that makes the biggest difference for me when I've had a connection with the family" [S7].

Family members able to attend room blessings found the experience provided them with the opportunity to connect with staff members and offered significant benefits. "It was very good to come back to the room where he died and with people who had been involved in his care. It was very reassuring that we were all in the same boat. It offered a first step in closure which was important to me. My children couldn't come because they were working … I would have liked to have had them there so they could feel the same things I was feeling" [F7]. Another family member commented: "It was part of the healing, not just for me but for our children, to know that staff would gather and that they would bless that room where their beloved father had

died, that meant a lot to them, it really did, and it meant a lot to me too" [F8].

### Coming Together as a Community Recognizing and Including All Members of the Care Team (Staff, Residents, Families)

An invitation to a room blessing ritual is extended to staff, residents, and family members of the deceased resident. Facilitators try to organize the timing of the room blessing to accommodate the schedules of as many of the interested parties as possible. Staff, residents, and families expressed appreciation for the inclusiveness of the ritual, which recognizes that staff, family, and residents operate as a team. One staff member described this inclusivity: "It's open to anybody, not just the nurses, it's not just residents, anybody can go to that … it's nice that it's not just focussed on staff" [S8]. A resident stated: "You know, the interesting thing is we never say who we are at those meetings, but that's probably not necessary either, we are just another friend, just another resident … we all become one family in a way which is an advantage. We aren't identified as patient or nurse. It's very interesting" [R7]. This inclusivity aided the bereavement process by reminding attendees that others shared in their grief. One family member described this adeptly, "I think the spiritual part of it was that we were all in this together and my situation wasn't unique. It was important to be aware of the fact that other people had gone the same course and its part of life" [F7].

### Welcoming the Incoming Resident

The final element of the room blessing ritual was to pray for the new resident and for room blessing attendees as the ones responsible for welcoming the newcomer. A card, often accompanied by a token (e.g., small angel, butterfly, sun catcher), was left for the new resident to let them know that the room had been blessed. Some staff members felt that this final part of the ritual helped to bridge the gap between mourning the deceased and welcoming the new resident. One staff member explained: "I always feel good. I always like it because I think it finishes the loop from when someone new is here to when they are gone and entering the new phase of welcoming someone else. It's a wonderful acknowledgement of the person that was there and a new beginning for the new person. I think it is a wonderful, wonderful blessing!" [S4]. A similar sentiment was expressed by another staff member: "It's a chance to make the space fresh and new and to bless it for the next person. I think it is a mark of respect for the person coming in, it's turning the page" [S9].

## Contributing to the Overall Impression that the Organization Lives Its Mission and Values by Providing Compassionate Care

Staff, residents, and families all felt that the room blessing ritual said something about the LTC facility. Many appreciated that the death of the resident was acknowledged, respected, and honored. One staff member said, "It's a mark of respect to the person, the care, respect of life at all stages … This is part of acknowledging that we don't just put the sheets in the laundry and clear the room and the next person comes in. There's a respect for saying good-bye to the person that's very important" [S9]. Similarly, a resident commented: "It's a very nice tribute to everybody you know, when they go, at least somebody cared enough to get together and say something" [R1]. Participants also felt that the room blessing showed that life is valued by the facility, not just the lives of residents but the lives of the staff and families who care for them. One staff member stated: "Shows that [the organization] values each and every person, especially our residents and their families, and the neighbourhood itself as a community which includes the staff and everyone … It shows where our heart is, who we are. We value life …" [S4]. One resident's comment about the organization was: "It makes you feel happy that the organization has taken the trouble to organize this kind of ceremony. It shows that it is worthwhile to say goodbye" [R8].

## Challenges

Overall, most staff, residents, and family members found the experience very positive and supportive, and indicated they would not change anything about the room blessing ritual. Participants identified some challenges related to the attendance and practice of the room blessing ritual; specifically, that the necessarily short notice was sometimes problematic for participants, especially for staff and families: "I don't like the fact it happens very quickly and sometimes we can't go if you have something else on" [R7], "You can't find the perfect time that everybody is able to go" [S5]. Staff reported feeling guilty when they were unable to attend: "I don't always get to all of them and I feel guilty about that sometimes. I feel guilty that I have to pick and choose, and it's not a personal pick and choose, it's just what happens to be going on at the moment" [S6]. Some family members found it difficult to fit the room blessing into the many tasks required of them at that time (e.g., funeral arrangements, cleaning out room, informing businesses). "[The] room blessing was day after funeral. It was very nice – everybody said positive things about my father and it was great but I got those positive comments from the funeral so I didn't feel I needed them" [F2].

Although holding the room blessing in the room of the deceased was an important and highly valued element, many participants noted that room size affected the ability to conduct the room blessing with larger groups: "Sometimes we have it in a larger space because we know that person had a lot of friends. I never think it is as good. There isn't the intimacy of the room itself and the person's kind of spirit in their own room. So I never really liked the dining room as well but it's a good idea because some people do have more contacts" [R7].

## DISCUSSION

Post-death rituals, such as funerals and memorial services, offer opportunities to share grief, express condolences, and reflect on the meaning of life (Kollar, 1989). In the LTC setting, however, where death is frequently experienced, the opportunity to attend such rituals is limited. Close relationships often develop among staff, residents, and family members; therefore, when a resident dies, the loss felt by staff and other residents is significant.

The room blessing ritual practiced at SJHCG addresses many of the bereavement needs of staff, residents, and family members alike. Notably, the room blessing ritual acknowledges that the individual who has died is unique and is valued and respected. Equally important is the inclusiveness and openness to participation of all members of the care team. Perhaps most significant, members of each participant group (i.e., staff, residents, and family members) mentioned that "it isn't right to just disappear." The room blessing is a clear statement to all involved that residents will not and need not be readily forgotten.

Acknowledging death through this community ritual affirms the fundamental link that exists between the deceased and those still living. For staff, the practice of the ritual within the LTC facility signifies that they are allowed to have relationships with residents, thus, authenticating their feelings of loss and their need to express that loss. For residents, it acknowledges a shared and meaningful coexistence between residents in an LTC home where significant relationships develop. It also signifies that they too will be remembered once they are gone. Family members derive comfort from knowing that their loved one was valued and appreciated by staff members and other residents of the LTC home and that they are not alone in their grief.

Participation in the room blessing ritual helped to make the death "real" and allowed for feelings and emotions to be expressed and acknowledged rather

than suppressed. One staff member commented that the room blessing helped to inhibit the desensitization that often occurs among healthcare staff who often deal with death as part of their workplace experience. A few staff members mentioned that, when they are unable to attend a room blessing, they try to do something for themselves to acknowledge their loss. This underscores the importance of formal supports to address bereavement needs.

The provision of the room blessing ritual by SJHCG sends the message that the organization as a whole cares about all of its members. Staff in particular took pride in being able to show respect for the deceased and to provide comfort to other residents and family members. By allowing staff and residents to express condolences to family members, the ritual strengthened the sense of a caring community among residents and staff.

The reflection and story sharing element of the room blessing ritual was the most valued for all groups. This reflection not only offered a healthy emotional release, it also served as a learning opportunity for those present, as many of the stories told had not been shared before.

We interviewed a selection of participants who had attended at least one room blessing ritual. Although these events were well attended, we do not have a sense of how many staff and residents have elected not to participate in the room blessing ritual to address their bereavement needs. Individuals who refrain from using this support offered by the facility may have additional bereavement needs that are not being met. A comprehensive model for end-of-life care in LTC should provide a range of supports to meet the needs of all staff and residents.

Previous research examining models of bereavement support for staff and residents in hospice and palliative care settings have been extensive; however, few studies have described the use of such models within LTC facilities, despite the obvious need for these supports in these settings. Rickerson et al. (2005) found that most staff would use additional sources of support if it was offered, and that they preferred attending a memorial service if one was offered at the organization or sending a condolence card. A few studies have described conducting memorial services within LTC facilities, some conducted on the unit in which the death has occurred (Moss et al., 2003; Anderson & Gaugler, 2007); however, the general picture of LTC is one of a paucity of grief and bereavement programs or rituals to support the healthy grieving of residents and staff (Murphy et al., 1997; Burack & Chichin, 2001; Moss et al., 2003;Touhy et al., 2005; Anderson, 2008; Van-Hein Wallace, 2009).

LTC facilities are serving older and more seriously ill residents, which has resulted in organizations that are increasingly resource constrained. Given the relationship between the emotional health and job satisfaction of staff to the overall quality of life for LTC home residents (Anderson, 2008), models for managing end-of-life care need to be developed that serve the needs and promote the emotional health of all care team members, including staff, residents, and family members. Formal supports to manage bereavement needs are critical (Moss et al., 2003; Goodridge et al., 2005), simple, and cost effective, and therefore, should be included in these models. These models also must honor the attachment and commitment of staff to residents and of families of residents to each other.

## CONCLUSIONS

Bereavement rituals, such as the room blessing ritual, can be incorporated into such a model to provide an essential formal support for staff and resident bereavement. The room blessing ritual is highly valued by staff, residents, and family members; it does not require a large investment of time or resources, and it can easily be incorporated into daily practice routines in LTC organizations. The ancillary benefits of supporting bereavement needs is the increased capacity of staff to provide compassionate high quality care, the assurance for residents that the deceased, and by extension themselves, are valued by the organization, and the fostering of a stronger sense of sharing and community within the organization.

## ACKNOWLEDGMENTS

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