

Funk, L.M., Waskiewich, S., & Stajduhar, K.I. (2013-2014) Meaning-making and managing difficult feelings: providing front-line end of life care. *Omega: Journal of Death and Dying*, 68(1), 23-43. doi: <http://dx.doi.org/10.2190/om.68.1.b> [Copyright Sage Publishing]
<http://ome.sagepub.com/content/68/1/23.full.pdf>

Meaning-making and managing difficult feelings: providing front-line end of life care

Funk, L.M.,¹ Waskiewich, S.,² and Stajduhar, K.I.³

¹Funk, L.M., PhD. [corresponding author]. Assistant Professor, Department of Sociology, University of Manitoba. 307-183 Dafoe Road, Isbister Building, University of Manitoba, Winnipeg, Manitoba R3T 2N2. Phone: 204-474-6678; Fax: 204-261-1216 Email: Laura.Funk@ad.umanitoba.ca

²Waskiewich, S., MA. [posthumous publication]. These data were collected for Ms. Waskiewich's Interdisciplinary Masters Thesis research at the University of Victoria, Canada.

³Stajduhar, K.I., PhD, RN. Associate Professor, School of Nursing and Centre on Aging, University of Victoria, PO Box 1700, STN CSC, Victoria, British Columbia, Canada V8W 2Y2. Phone: 250-721-7487; Fax: 250-721-6499; Email: kis@uvic.ca.

ACKNOWLEDGEMENTS. We thank the RCAs who contributed their time, as well as Elizabeth Causton, who assisted with interviewing and review of this manuscript. The guidance of Heather Cook, Dr. Holly Tuokko and Dr. André Smith are also acknowledged, as is the advice of Dr. John Bond. Ms. Waskiewich was supported by a University of Victoria Interdisciplinary Student Award; Dr. Stajduhar is supported by a New Investigator award from the Canadian Institutes of Health Research and a Scholar Award from the Michael Smith Foundation for Health Research.

ABSTRACT. Managing grief and difficult emotions related to end of life (EOL) care is an often under-recognized part of the work of resident care aides (RCAs). In this interpretive analysis we explore the shared and socially constructed ideas that eleven RCAs in one Canadian city employ to make sense of death and the provision of EOL care. RCAs spoke of personal challenges involved in witnessing death and experiencing loss, as well as helplessness and frustration when they could not provide quality EOL care. RCAs invoked “consoling refrains” to manage grief, including “such is life,” “they are better off” and “they had a full life.” To manage guilt and moral distress, RCAs reminded themselves “I did my best” and “I experience rewards.” Though these ideas help RCAs, some may need to be reframed through coaching and mentorship, to prevent unintended negative effects on care or the reproduction of ageist beliefs more broadly.

Population demographics, technology and health care service delivery have been re-shaping the nature of older populations in residential care facilities. More residents have chronic life-limiting conditions such as dementia, leading some to suggest that “long-term care facilities will become the hospices of the future” (Abbey, Froggatt, Parker, & Abbey, 2006: p.56). In Canadian residential care facilities, the most substantial portion of direct care is provided by resident care aides (RCAs). As a result of frequent and sustained contact with residents over time, RCAs frequently report developing close, family-like relationships with residents (Moss, Moss, Rubinstein, & Black, 2003; Wilson & Daley, 1998). Though this may help RCAs provide better quality end-of-life (EOL) care (and indeed, may sustain them in their work), it can also be a ‘double-edged sword’ entailing considerable grief and distress when a resident dies (Ersek & Wilson, 2003; McClement, Wowchuk & Klaasen, 2009).

Staff members in residential care settings frequently lack opportunities to grieve resident deaths (Kaaslainen, Brazil, Ploeg & Martin, 2007; Moss et al., 2003) and many desire greater practical and/or emotional support after a death (Hanson, Henderson & Menon, 2002; Katz, Sidell & Komaromy, 2001; Katz, Sidell & Komaromy, 2000; Rickerson, Somers, Allen & Lewis, 2005). Bereavement support in these facilities is often non-existent or poorly resourced, due in part to resource constraints and an inability to recognize staff bereavement needs (Moss, Braunschwig & Rubinstein, 2002; Katz, Sidell, & Komaromy, 2001). When deaths and relationships are unacknowledged, grief may be disenfranchised, which may have negative effects on personal growth, as documented in one study (Anderson & Gaugler, 2006).

In addition to grief, RCAs providing EOL care deal with difficult emotions such as helplessness that can be involved when watching a resident suffer (Goodridge, Bond, Cameron & McKean, 2005; Palan Lopez, 2007). Additionally, RCAs may work in environments with inadequate staffing, lack of supervision, high turnover, low morale, and heavy workloads

(Kayser-Jones, 2002; Kayser-Jones et al., 2003; Quadagno & Stahl, 2003). These issues add to the challenges providing care to residents with complex and diverse care needs, and to the difficult emotions faced by workers.

In this article, we draw on findings from an in-depth qualitative study to explore the ways in which eleven RCAs manage difficult emotions in the provision of EOL care. The approach is interpretive, drawn from a social constructionist theoretical perspective and principles of social psychology. In line with this approach, our focus is on the ways in which participants talk about their experiences with death and dying, as a key aspect of meaning-making. Few Canadian studies have applied such an approach to this topic, yet doing so may generate new knowledge regarding how care aides experience dying and death in the context of their work.

LITERATURE REVIEW

Not only does the vast majority of bereavement research focus on family members, but it also tends to adopt a positivistic rather than constructivist orientation. Though individuals might be asked to describe the ways they typically experience bereavement, seldom is a more indirect analysis of *how* they talk about their experiences considered itself to yield important information about coping or meaning-making.

Some researchers have focused on how family caregivers face challenges such as bereavement through creating meaning and identifying positive outcomes - for instance, by constructing caring as a privilege, as enhancing relationship, and as providing a sense of accomplishment (Enyert & Burman, 1999; Gottlieb & Wolfe, 2002; Grbich, Parker & Maddocks, 2001; Holland, Currier and Neimeyer, 2006; Hudson, 2004; Milberg & Strang, 2003; Strang & Koop, 2003). As an example, bereaved informal carers interviewed by Wong and Ussher (2009) accentuated positive aspects of care in order to construct and assign positive meanings to loss.

Funk and Stajduhar (2009) propose that “participants’ talk about their caregiving experience is simultaneously an articulation of experience that draws on broader ideologies, as well as an attempt to cope with perceived experience” (p.861). An interpretive approach to interview analysis operates on the assumption that in articulating their experiences, interviewees are trying to show how their action makes sense; they are accounting for their feelings and actions and justifying them (Atkinson, Coffey & Delamont, 2003; Gubrium & Holstein, 1997). Such an approach overlaps to some extent with the psychological study of meaning-making. For instance, Davis, Nolen-Hoeksema, and Larson (1998) drew on longitudinal data from bereaved family members, identifying two meaning “construals,” each with independent positive effects: “making sense of the event and finding benefit in the experience” (p.561).

Sinding and Aronson (2003) note how bereaved family caregivers frequently invoked idioms or ‘consoling refrains’ such as: “she didn’t suffer”; “they did everything they could”; and “it was for the best” (p.103). The authors propose that this kind of talk helps to contain regrets, sorrow and responsibility, as well as to “narrow the distance between the ‘good death’ and the death research participants witnessed” (p.103).

RCAs might invoke similar ‘consoling refrains’ to manage and contain difficult emotions involved with death and dying. Yet few studies have specifically applied an interpretive approach to bereavement among health care staff in residential care settings. Some research has identified the importance of meaning-making interventions for palliative care nurses, recognizing its value as a strategy for coping with existential and emotional demands, and potentially enhancing job satisfaction (Fillion et al., 2009). Other research has identified how hospice volunteers cope with bereavement in part by drawing on their religious faith and viewing death as a necessary process and a merciful release from suffering (Dein & Qamar Abbas, 2005).

Though not specific to death and dying experiences, U.S. researchers Anderson and colleagues (2005) identified two mental models employed by resident care assistants to interpret behaviours and events and to respond to these in their practice. These included “the golden rule” (to respond as they would want someone to do for them) and “mother wit” (to treat residents as they would their own children). Applying these models facilitated RCA advocacy and affection towards residents, yet sometimes generated inappropriate responses “such as infantilization and misinterpretations about potentially undiagnosed conditions such as depression or pain” (p.1006).

In another U.S. study (Moss, Moss, Rubinstein & Black, 2003) direct care staff emphasized “family-like thoughts, feelings, and behaviors toward long-term residents” (p.S290), particularly as death approached. This family metaphor provided a cultural script that acted as “a counterweight to the cultural and institutional milieu that tends to pay little attention to the impact of resident deaths on the work world and personal world of staff members” (p.295). By drawing on the metaphor of family, staff members prioritized their relationship with the resident and the emotional side of their work, validating the importance of their loss and facilitating their expression of grief. In a related publication, Black (2004) described how direct care workers coped with bereavement by drawing on personal experiences and ethnic, religious, and spiritual beliefs about life and death. These frameworks helped them maintain a sense of dignity in their relationships and their work and prioritize the importance of knowing and loving residents, which helped them provide quality, compassionate care. Likewise, Black and Rubinstein (2005) illustrated how socio-demographic characteristics, traditional and idiosyncratic belief systems (including spiritual beliefs) and experiences with death outside of residential care settings shaped care providers’ constructions of meaning and reactions to the deaths of residents.

With the exception of the above-noted studies, there has been little application of an interpretive approach to bereavement among RCAs, particularly in Canada. Such an approach

may generate new insights into the shared beliefs and interpretive frameworks that care aides use to manage feelings about death and dying. It may also assist in distinguishing between the kinds of meanings that could be promoted among care aides, and the kinds of meanings that may need to be reframed or questioned. As such, in this article we apply an interpretive perspective to the analysis of meaning-making among eleven resident care aides who provided EOL care in three residential care facilities in Victoria, Canada. Attention is directed to how RCAs talked about their experiences, and to the larger cultural and social frameworks they applied in order to make sense of their experiences and manage emotional demands such as grief.

METHODS

Participants included certified resident care aides (RCAs) who had worked full time for at least one year in a residential care facility and had experience providing EOL care to residents who had died (timeframe and/or frequency was unspecified). They were required to be at least 19 years of age, speak fluent English, and reside in the study setting (a Western Canadian urban setting). The Director of Residential Services with the local health agency facilitated recruitment. A presentation was given to residential care managers in the agency, outlining the study purpose and asking permission to recruit RCAs within facilities they managed. Three managers volunteered their facilities as study sites. All facilities experienced an average length of stay for a resident of about one year, suggesting RCA staff were likely frequently exposed to death. Presentations at staff meetings were conducted in these facilities, recruitment information was posted on facility bulletin boards, and letters of invitation were left on the units. The invitation asked for those RCAs who had provided care to a resident who had died at their place of work; willing participants were asked to contact the researcher directly.

We conducted individual, in-depth, semi-structured interviews with eleven RCAs. Informed consent was obtained in writing, and the location of interviews was based on protecting participant anonymity (e.g. away from the facility or as private as possible within the facility). Interviews were conducted face-to-face and lasted about 1-2 hours. Guiding questions were used, such as: “What it is like for you to provide care to residents nearing death?” and “What sort of impact does providing this care have on you?” Participants were asked to speak about the practical and emotional challenges they faced, and to elaborate with examples and descriptions, as well as recommendations. Interviews were audio-recorded with participants’ consent and transcribed verbatim. For descriptive purposes, demographic information was also collected (ethnicity; education; gender; marital status; age; employment status and years of experience).

The analysis involved several steps. First, we examined the kinds of experiences and emotions that participants described as difficult or challenging in their work. Then, we considered the ways they told us they managed those emotions and experiences. Following this, we examined the common (e.g. shared) ideas that recurred in participant talk about resident deaths and EOL care. Pieces of data were sorted and grouped by these initial interpretive themes, so that similar data on the same theme could be viewed together. We then sought to clarify similarities and differences between these ideas, to refine the categorization of these ideas and identify subthemes and inter-relationships. For instance, some ideas were more closely associated with talk about death, and some ideas were more closely associated with talk about work-related stressors. Throughout, we consider how participants employed these ideas (e.g. in response to which questions; was it used in different ways at different times; was it a recurring emphasis).

FINDINGS

Sample Description

A total of seven female and four male RCAs participated in the study. The average age of the sample was 48 years, and this ranged between 23 and 61. Five described themselves as married or the cohabiting, two widowed, three divorced, and one never married. Seven were employed fulltime (including one casual employee who worked full-time hours). All but one of the participants had certification as an RCA through a college program. One participant had no formal training, but learned on the job years ago and was 'grandfathered in' after certification requirements were introduced. Eight participants reported having had at least some formal training in palliative or end of life care, ranging from content currently included in their RCA training, to professional in-services or seminars, to courses. Two others described learning about EOL care on the job. Participants' years of experience working in health care or long term care ranged from two to 45, with an average 22.5 years (median: 21 years).

After documenting RCA descriptions of the sources of difficult emotions in their work, we turn to an in-depth interpretive analysis of how RCAs managed these emotions.

Witnessing Dying and Experiencing Loss

Witnessing a long, difficult and suffering dying process is a difficult experience for RCAs, who related this to painful, sad and unpleasant feelings. As one RCA noted, "to watch somebody die is so much nicer when they're peaceful. When they're struggling and fighting it's horrible to watch ... They're not laying there nice and peaceful like they should be." Difficult deaths often involve situations that are difficult to witness (e.g. screaming; pain; loss of control of body functions; unpleasant smell; difficult breathing). As another RCA described, "it's not always nice to watch somebody die, especially if they fill up with fluid and they're all gurgling and fighting for breath." Several RCAs further referred to difficult emotions invoked when working with deceased bodies (e.g., as "eerie" or frightening).

The death of a resident, particularly one to whom the RCA was emotionally attached, can generate intense feelings of grief and loss for RCAs. Some of these deaths may be a particular shock when they are unexpected, and the RCA was not able to emotionally prepare or say their goodbyes to the resident. One RCA spoke of how “if I know somebody’s dying, you start your grieving process from the time you know – not from the time they die.” Participants also described how they feel like family or friends to some residents, as they work with them closely over a long period of time, interact with, and develop relationships with them and feel part of their life. This was reinforced by a common belief that dying persons should be treated by the RCA like they would treat one of their family members: “they become like family to me because I treat them as if I would want my family to be treated if they were in a home.” Particularly for residents without visiting families, some RCAs may view themselves as ‘substitute’ family.

Close bonds and emotional attachments contributed to RCA grief when a resident dies, even for RCAs who were experienced and generally believe they cope well. Not only the loss, but watching the resident suffer was described as difficult. Further, where RCAs develop close relationships with family members over time, this can be emotionally challenging, as in: “that’s really hard too when somebody passes on the family is gone too and you miss all the family too.” For instance, one RCA referred to how he still worries about how one resident’s wife managed after her husband’s death.

Finally, the loss of a resident can also be acutely felt when RCAs have recently experienced deaths in their personal lives, as with one RCA who lost her husband, and described how at work: “I didn’t think I was going to get through. I thought I was going to have to quit to be perfectly honest... I thought ‘I just can’t take one more death.’”

Moral Distress in Providing EOL Care in Residential Care Facilities

RCAs described several sources of stressful or negative personal experiences related less to death itself and more to the provision of care to dying residents in residential care settings. First, they spoke of particularly difficult aspects of this work, including having to tell families about the death of a loved one; witnessing family tensions; and providing care for “miserable” residents or those with behaviours such as aggression. Feelings of guilt were also described with regards to providing EOL care (including personal care) to a resident they do not know well or even dislike, as in: “I always feel a little bit guilty...maybe I should have liked them better than I did...I couldn't love them.” One RCA described the effort involved in “being professional over emotional” and remaining calm with difficult residents or families. Some care aides expressed additional fears that a resident might die while they are turning them.

Another commonly cited source of stress and difficult emotions in providing EOL care was when RCAs were unable to help dying residents - they felt helpless or frustrated in the face of suffering. A frequent concern was being unable to spend more time with dying persons (especially when family is unavailable or the resident is very upset), which they strongly desired. A lack of time was the predominant challenge described by RCAs to providing good quality care. This has a personal impact for RCAs, as in: “you always feel like you can't look after them properly or spend time with them.” One participant described how that morning, she had done some basic care for a dying resident, and then become busy caring for the others on her workload: “by the time you get back to him it's been too long. So then that makes me feel guilty that I'm not being a good provider for him.” Other RCAs described feeling dissatisfied, helpless, upset, sad and/or stressed in similar situations, as in the following excerpt: “I don't like it. I feel bad at the end of the day.” Even when RCAs make extra time to care for the dying resident, guilt may remain, since finding the time can often mean taking it away from others: “I feel that I'm neglecting somebody else to be there for them.”

From this perspective, RCAs commonly referred to families as “a big help,” in part because knowing that someone is present with the dying person alleviated their own feelings of helplessness and guilt, as in: “you don’t feel like you don’t have time for this person because there’s somebody there”; and “I feel a little less guilt because I know somebody’s with them and they’re not alone.” Many RCAs expressed similar wishes for volunteer help to sit with dying residents, as in: “That would be a great help. I would feel much better knowing that my patient has got that...extra attention and they’re not going to be by themselves.”

A lack of time to spend with dying residents is especially difficult for RCAs because often, the only thing an RCA can do for a dying person (who may be in pain) is to sit with them and provide the most basic of comfort measures. For some participants this contributed to a feeling of “not doing enough.” One RCA described how: “it’s terrible to see somebody in pain like that. And you can’t do anything about it, except just be there, hold their hand.” Another RCA noted that if the dying person is in pain, “I feel like I haven’t done my job well because, all they want is some relief from this pain and I’m not the person that’s able to do that for them.”

In some situations RCAs may believe they contribute to the suffering of a dying person. One RCA spoke of her personal difficulty when one of her favourite residents was dying and they could not make her comfortable – they were supposed to offer her “thickened fluid” as long as possible but she was sputtering: “here I am half choking her.” In addition, this RCA accidentally tore out a resident’s subcutaneous butterfly (for intermittent pain control): “I felt so bad.” Further, in providing personal care RCAs are frequently tasked with moving or turning residents, an action can cause dying persons additional pain. This was characterized as upsetting and disturbing for many RCAs. One buffering factor noted in this regard is a facility policy that specified that two RCAs must help move the dying person.

Managing Difficult Feelings: RCA descriptions

RCAs spoke of how they managed the above-mentioned stresses through various means. Though self-reported means of coping were not the primary focus of this study, we describe a few examples in this section, as illustrations. For instance, some RCAs spoke about facing the impending death of a resident through “saying one’s goodbyes” to a dying resident and achieving “closure.” Closure was facilitated through spending time dying residents, as in: “when you are helping someone pass and just keeping them comfortable, it’s also our way of doing probably our own grieving in that few days, and our own way to let go.” Another participant noted: “I usually do say goodbye to my residents if I know they’re dying...it’s for me really more than them.”

In contrast, other RCAs appeared to continue to construct a sense of ongoing connection to deceased residents, perhaps in order to cope. Two RCAs, for instance, referred to maintaining social contact with the bereaved family members. Other RCAs described keeping the deceased resident’s memory alive through treasuring something the resident made for them or a copy of their obituary. In addition, one RCA expressed a belief that when a person dies, a part of them stays with and remains connected to her; another drew on her personal experience (and that of others) to reinforce her belief that people’s spirits or ghosts “hang around” or “come back.”

Another way in which RCAs described managing difficult emotions is by trying to ‘detach’ themselves. For instance, one RCA spoke about his past difficulties with his grief over the death of a resident he was attached to. After this, he “pulled [him]self back from all my patients. I try not to get too connected to them and I try not to get too emotionally involved with them because I found that that one was a very hard death for me.” Another RCA drew on her belief that a person’s spirit often dies a few days before their body; this belief was reinforced for her by changes she observes in a person’s face as they near death (and ‘sometimes their personality disappears’). She adds “your personality is your spirit really. If you lose that, there’s

nothing. There's just a shell. That in a way helps because the person is no longer the reality that you knew...you feel like they've actually gone so you're just sort of taking care of a body."

Along similar lines, another RCA spoke of how it is easier to stay detached when caring for residents with dementia: "so I just go in and do my job and make sure they're positioned appropriately and that's about all I can do in situations like that." For these RCAs, depersonalizing the resident served to help them manage their difficult feelings about death.

In contrast to those who spoke about detachment, another RCA spoke about her own experience with her first death at work, which was also deeply upsetting. As a result of that experience, she reflected that: "either I have to shut my emotions off so I can deal with all these deaths, or I have to make a decision to love them anyway and maybe grieve when they're gone." Rather than avoiding developing close attachments to residents, she acknowledged her grief and accepted these emotions as an integral part of her self and her work: "I've always said if it doesn't affect me, I'm leaving, I'm burned out."

RCAs also spoke of addressing their emotional needs through talking with co-workers or their own families, de-stressing through exercise - or less healthy habits -, and when possible taking time for their grief and reflection (often they can only do this after they leave work). Rarely did participants refer to seeing a counselor. Though some RCAs speculated that their co-workers may at times prefer to 'bottle it up,' a common recommendation for facility management was to ensure that sufficient bereavement support structures are in place for staff. This could include having a therapist or counsellor available to speak with staff members on site ("not to send us to somebody we've got to wait a week to see"), or allowing a 15 minute break for RCAs who have just experienced a resident death. It was noted that a sense of closure could also be promoted for both staff and residents through memorial events.

Managing Difficult Feelings: How RCAs make sense of death

The primary focus of this paper is on the ways in which RCAs manage difficult emotions through drawing on shared beliefs and ideas about death and dying. These ideas were expressed in the interview context; however, participants sometimes noted how they employ these ideas when communicating and interacting with coworkers after a resident death. The nature and content of the predominant ideas we identified are analyzed in-depth below, and critically reflected on in the discussion.

Such is life. One way in which RCAs coped with death is by normalization – in other words, death is a normal part of life, and a common occurrence in residential care settings. Participants appeared to draw on this idea to remind themselves and their coworkers that deaths are to be expected and accepted. For instance, RCAs invoked phrases such as: “it’s part of life”; “that’s what they’re here for right”; and “we’re going to be born, we’re going to die one day.” One RCA expressed: “with these people, as they come in, I *know* I’m going to watch them go out and there’s only one way out of that place. So I’m prepared for it.” A sense of preparedness and acceptance may be enhanced when RCAs have many years of work experience, as with one RCA who expressed that he has seen so many deaths that he accepts it: “this is just all the way life goes.” Another RCA spoke of how it is personally difficult when a bed is re-filled quickly after one resident dies: “We always say, ‘Oh, it’s too soon.’ But, there are no beds. Everybody’s waiting for a bed so we just go, ‘such is life.’” Likewise, another RCA described the practice of quickly refilling beds as “disrespectful” and personally difficult for her. To her the action seems “just about the money” (i.e., if the deceased resident’s account is already paid for until end of month). However, she then normalizes and excuses the practice in consideration of constrained resources: “but I realize there’s a need out there in the community as well and the wait lists are screaming.”

They are better off. Another way in which RCAs coped with death is by reminding themselves that the resident is “better off.” For those with particular religious backgrounds, this might encompass a related belief that the resident is going to “a better place,” as in, “it helps me to turn my patients over to God.” One RCA expressed: “that sort of helps me knowing that they’re better and not suffering...you know they’re in a better place so you can move forward.” Other RCAs stated beliefs such as, “all those that left before us are there waiting” ; or “you’re going off to another life that might even be better than what you came from.”

In addition, there was a shared understanding that when dying residents are in pain, suffering and have a poor quality of life, death brings a sense of relief, solace, and even moral justice. For instance, one RCA expressed that for residents with low quality of life and pain, “then it’s their time to die, then I don’t feel bad. I think it’s sometimes a blessing.” It is possible that the idea of ‘relief from suffering’ is tied to a sense of relief that the RCA themselves no longer has to watch the suffering of the dying person (which was described as difficult). For example, one RCA described sudden deaths as “almost like a relief because you didn’t have to watch them suffer and everything.” Another RCA stated: “they’re *safe* too when they die. No more pain. No more being scared or terrified of being alone.” RCAs further reinforced this belief by describing how they have heard some residents expressing their wish to die. One RCA added: “even if they didn’t tell us, just myself, I wouldn’t want to be there so why would they?”

A sense of death as a “blessing” and relief from suffering was tied to beliefs about dying old age, disability and dementia as in: “most of them are old and have dementia so I know it’s their time to go. There’s really nothing but suffering for them in their lives.” Another RCA expressed his dismay about extending the life of the elderly who experience stroke, dementia, and are restricted in activities of daily living, with no quality of life: “we keep plugging them in with antibiotics and just letting them keep existing.” Other RCAs spoke of symptoms affecting the

quality of life of elderly residents such as depression, fractures, loneliness, ulcers, cognitive impairment, being bedridden, and having discomfort and pain (referring e.g., to difficulties with pain management). One RCA expressed: “they’re not just going to be turning from side to side and looking at walls any more. They’re going to be gone on their next journey, whatever that is, or maybe just out of their misery, whatever you believe.” Another RCA, referring to how it helps her to know “they’re better off,” was asked to clarify, and responded:

A lot of people...they’re laying like in a nursing home in a bed. They don’t even know who they are. ... they’re so unsettled or they’re in pain or... those are the demented ones. The ones that are with it, they’ve got their brain but they don’t have a body. The bodies are in a wheelchair. They can’t walk. They can’t do this. They can’t do that. They’re unhappy. They don’t want to be there. So when I say they’re in a better place it’s because they’re unhappy here. So hopefully they’re in a better place over there because nobody wants to be in our hospital.

This same participant reinforced this belief by indicating that many people tell her they want to leave, and even try to escape. She added that even residents that are more mobile don’t really want to be there, but that it is often simply too expensive to be at home.

They had a full life. RCAs also managed their emotions by emphasizing that the person has lived a good, full, and/or long life. This helps impute a sense of fairness to the situation. In this regard participants often invoked contrasts between the deaths of elderly persons and those of younger persons, which were viewed as more upsetting because younger persons “have not had their life” or fulfilled their potential. A common sentiment was that RCAs could not personally work with dying persons of younger ages. In contrast, older persons have “lived their full life”

and “their time is up” – by focusing on this sentiment, RCAs coped with deaths in residential care settings. For example, one RCA expressed that when a resident is dying: “It’s sad, because they’re dying and you’re going to lose them, but, most people have lived a long life.” Another noted: “when they’re older they have to die sometime so I don’t feel bad for them.”

In addition, one RCA referred to how bereavement is easier if a resident has had a happy or good life – by focusing on what she knows about that person and their interactions, she appears to strive towards the conclusion that they have had a good life. Likewise, another RCA focuses on the “happy things” that have happened to the resident in their life, again reinforcing the idea that they have had a good life.

I did my best. The “consoling refrains” mentioned above represent ways in which RCAs managed feelings of grief and loss in residential care settings. Yet RCAs in our study also expressed a sense of helplessness and frustration in being unable to provide quality EOL care. To manage these feelings, RCAs focused on aspects they were able to control and the positive ways they were able to help the dying resident. One RCA related the story of a challenging death she experienced early on in her career. She was very attached to the resident and upset. In these early years RCAs were required to change, clean and prepare the body for the morgue. Though this experience was difficult, she added: “I felt good doing it because I knew that she was going to her burial the way I wanted her to look.” Another RCA spoke of trying to cope with his knowledge that he would be causing dying residents additional pain when turning them for personal care by focusing “on the positive parts of the care...I knew that once all the turning was done, she’d be clean and more comfortable. So I was definitely rewarded from that, just being able to make a person in that much pain feel more comfortable. There was some satisfaction with that.” Likewise, another RCA referred to how maintaining some ‘detachment’ involves reassuring himself that “I know that I’m doing all I can, within my scope of practice.”

RCAs expressed that by doing the best job they can to help make residents comfortable and promote a gentle death, their ability to manage difficult feelings is enhanced (and they experience a sense of reward in the job when they are able to help). For instance, one RCA emphasized the importance of knowing she did her best:

...at the end of the day, I feel good about my day even if I did watch a good friend die. I know that I did what I could. And they were going to go anyways but I like to think that I made a difference. It wouldn't have been quite so comfortable a transition if I wasn't there. Which is why I really try to put something into it when it does happen because then I've got that to go home with. Instead of, oh my God, I forgot to do this.

One RCA described her personal difficulties watching someone in pain yet not being able to do anything but hold their hand. She believed that sometimes, whispering in their ear that "it's ok to go" gives dying residents the 'permission' they need to die (she has witnessed deaths a few days later in some cases). In the face of helplessness, a belief in the importance of 'giving permission' might help RCAs personally cope by gaining a sense of control, and facilitating their own acceptance of the death (as well as the resident's acceptance).

In part because of the important role that being able to help plays in their motivation to and satisfaction in their work, two RCAs noted that it was personally gratifying to receive positive feedback and gratitude from the family after a resident dies: "It just affirms that I'm doing a good job."

The importance of a sense of being able to help, for RCAs' emotional wellbeing, highlights the additional difficulties faced in the absence of sufficient time. In this situation, consoling refrains include "I did what I could," as in the following excerpt: "there's been times

where I just didn't have enough time to spend with the dying person and I don't like it. I feel bad at the end of the day but I let it go too because I know I did my best." In addition, this participant explained that she also tries to focus on those things she was actually able to do to make the resident comfortable.

I experience rewards. RCAs frequently cited sources of personal benefit from their work that can be viewed as helping them focus on the positive. RCAs commonly described how their work experience has taught them to appreciate the moment and live for today, as in: "we may really get a little bit more out of our lives because we know they're fleeting...I think we don't sweat the small stuff." Another RCA expressed: "if you want to do something, go and do it. Life's too short. That's what this job really taught me." RCAs spoke of coming to terms personally with death and their own mortality, respecting life and realizing one is not invincible. To a lesser extent they highlighted additional rewards of the job, such as meeting and interacting with different people. Referring to humorous interactions with residents, one RCA noted: "if you didn't see the funny side of your job I think you would go... I don't know what would happen." Another RCA expressed: "You have to love [the job] otherwise if you don't love your job and if you don't love working with people...you won't come back."

A related way in which RCAs appeared to manage the difficult feelings involved in EOL care was to emphasize personal benefits related to their commitment to an honourable task. Specifically, RCAs frequently referred to how it is, for them, a privilege, honour or gift to be part of the dying process for a resident. Dying and death are viewed as a special and intimate and personal time, and to be included in the process is viewed, for example, as "almost like a reward at the end of looking after for them for so long. Icing on the cake, you can say." RCAs linked this idea to their own coping, as with the following RCA who commented that though death is

sad, she is okay because “it’s an honour to have been with them...at that part of their life and to be there at the end.”

Carry on with your job. To deal with bereavement and work-related stressors, RCAs commonly described focusing themselves on the task at hand, and carrying on with their work. For instance, one RCA expressed: “I can’t come home and beat myself up over it or I’ll burn out and I won’t make it.” From one perspective, this could be viewed as a form of emotional avoidance through focusing on tasks, in contrast to a consoling refrain (i.e. something that RCAs tell themselves in order to cope). Yet RCAs frequently expressed that there was no other option but to carry on, suggesting it is not so much a practical coping strategy as a functional necessity. For instance, a common refrain was “you just have to keep going and working” and “you carry on with your day. You have to. It’s your job.” This subtheme was dominated by a sense of a lack of choice in the matter, in part because RCAs are not provided with work time leave to grieve the death of a resident. Instead, they must essentially ‘shut off’ their emotions to keep working.

Though some participants may welcome the enforced distraction from their emotions (and thus talk about a need to ‘carry on’ is a more active coping strategy), for others, carrying on with one’s job can be difficult after a death and bring further challenges. One RCA, for instance, notes how they are supposed to continue working with other residents, but not disclose to them that the resident has died. The challenge she faces is a kind of ‘emotional labour’ (Hochschild, 1983): “and you’re trying to talk to [another resident] who’s being really chipper and you don’t really feel like that.”

Perhaps in part to motivate their continued work, some participants invoked the belief that they needed to stay strong for the bereaved families, other residents, and the organization. For instance, one RCA spoke of having to “pull yourself together” to not cry in front of other residents; another noted: “you have to look after the rest of them. So you can’t have time to

grieve too long.” Another RCA expressed that “you could go home sick but then who’s gonna look after your residents that are there. That’s not fair to your co-workers – then they’ve got double the workload.” Such sentiments do appear to take on the quality of consoling refrains that some RCAs might use to cope with the challenges involved in ‘carrying on.’

As mentioned earlier, RCAs struggle to manage their commitment to ensuring a good death within the context of numerous challenges to doing so within the residential care environment. Some participants spoke about being unable to deal with the resulting emotions, but again, focused on their need to carry on in their job. Others spoke about using a similar approach to deal with challenging aspects of their work (e.g., dealing with aggressive resident behaviours): “I just do it.” Though such ‘stoic’ approaches may provide RCAs with a temporary distraction or relief from dealing with their emotions, several spoke about later needing to deal with the emotions, for instance when they return home from work.

DISCUSSION AND CONCLUSION

This is not a comprehensive examination of all possible ways that RCAs cope with bereavement and work-related stressors; many other forms can occur. Instead, the particular contributions of this article lie in an in-depth interpretive exploration of meaning-making strategies used by RCAs to manage their emotions, and the shared beliefs they use in this regard. Though the analysis of these data was not directed to the end-goal of making recommendations for RCA coping and support, we were nonetheless able to identify several ways in which they could do so, which will be the focus of our discussion here.

For many RCAs in this study, relationships with residents are seen as an important part of their work and as contributing to satisfaction. Yet when residents die, RCAs are rarely permitted or supported to fully grieve or cope with the loss; instead, emotional regulation and management

are required (Hochschild, 1983). In addition, RCA certification courses rarely comprehensively address the emotional challenges involved in providing care for dying persons. Yet EOL care is a significant part of RCA work, and RCA exposure to death will likely increase in the current context. Providers of residential EOL care should be supported in bereavement, to prevent burnout related to the stresses of loss, the work environment, and emotional labour. Our study confirms that RCAs tend to have little time for or supports available for grieving, yet may require such support. In their absence, RCAs rely on informal conversations with co-workers, deal with it at home, 'bottle it up,' or draw on shared meanings to interpret their experiences.

RCAs in this study experience difficult feelings related to death and loss, but also to resource (time and staffing) constraints that generate morally intolerable situations and affect their ability to provide quality care (Austin, Bergum & Goldberg, 2003). The term moral distress (Austin, Lerner, Meyer, Goldberg, Bergum & Johnson, 2005) has been used to refer to situations wherein institutional constraints (e.g., a lack of time; heavy workloads) make it impossible to pursue the morally right course of action (e.g. to fulfil a moral responsibility to the resident). Moral distress has been found to generate frustration, anxiety, guilt and stress reactions, hamper coping ability and lead to burnout (Austin et al., 2005; Casey et al., 2011; Ersek, Miller Kraybill, & Hansberry, 1999; Kaasalainen et al., 2007). RCAs in the present study wanted to provide better EOL care, but time and workload constraints impeded their ability to do so. Rather than dismissing these as the concerns of individual, "fussy" RCAs with overly high standards, there may be a need to address the system constraints that create barriers to the provision of quality EOL care.

Beliefs expressed by study participants were not only articulated within the interview, but were described as often shared among co-workers as they informally debrief deaths in residential care settings. Though some shared beliefs may assist care aides in managing and containing

difficult emotions, some may contain potential risks for the delivery of care, and others may further reinforce negative attitudes and perceptions of aging and dying. For instance, the normalization and expectation of death in residential care environments, while helpful for coping, might inadvertently contribute to a lack of attention to preventative care that may partly alleviate suffering, especially if palliative philosophies that support preventative approaches are not also emphasized (Österlind, Hansebo, Andersson, Ternstedt, & Hellstrom, 2011). Further, a belief in the moral fairness of the death of older persons (as compared to younger persons) might not only reflect but further reinforce ageist ideas that devalue older persons. Finally, we are concerned with how RCAs construct deaths as a welcome relief for the resident from pain, suffering and poor quality of life. Though this belief may be functional for the RCA, in our study we noted stereotypical and ageist beliefs that appeared to automatically equate any disability, dependency, dementia and dying with misery and suffering. This belief might obscure the importance of ensuring adequate attention to improving the quality of life of dying residents (e.g., through addressing and treating pain and depression). In line with the recommendations of Anderson and colleagues (2005), we might consider ways to work with RCAs to help them reframe particular interpretations (e.g., through group and one-on-one discussion and guided conversation with social workers and counselors), particularly where interpretations may have unintended effects on the quality of care. This could be built into grief support programs, for instance, in such a way that RCAs are encouraged to develop interpretations of death and dying that not only help them to cope, but do not contribute to broader ageist discourses nor affect the quality of care provision.

Some RCAs speak about coping with the impending death of a resident through “saying one’s goodbyes” to a dying resident and achieving “closure” through spending time with dying residents. A similar emphasis on saying goodbye (McClement, Wowchuk & Klaasen, 2009) and being there (Kaasalainen et al., 2007; Palan Lopez, 2007; Wilson & Daley, 1998) has been

documented by others. In part, then, a belief in the importance of spending time with dying residents, as part of quality EOL care (Waskiewich, Funk & Stajduhar, in press) may be related to RCA's own needs to cope. However, since RCAs were also content if other family members or volunteers spent time with dying persons (Waskiewich, Funk & Stajduhar, in press), the belief may transcend personal coping needs.

Another way in which RCAs describe coping is by trying to 'detach' themselves emotionally from dying persons; this has also been noted in other work (Hopkinson, Hallett & Luker, 2005). Though depersonalization can help with coping (via detachment), it may pose risks for the quality of care (as well as for the personal well-being of RCAs). In this respect it may be more helpful to encourage RCAs to acknowledge their grief, express their emotions, and to acknowledge and respect this as an inevitable outcome of relational work in residential care.

One way in which RCAs manage grief, helplessness and moral distress is to focus on aspects they are able to control and the positive ways they are able to help the dying resident, however subtle. Other research has also connected high satisfaction to perceptions that one is providing good EOL care (Goodridge et al., 2005); and discontent and frustration to a perceived failure to provide good care (Kayser-Jones et al., 2003). Hanson, Henderson, and Menon (2002) noted how nurses and assistants "wavered between feelings of hopelessness and pride in their ability to give good care in spite of poor working conditions" (p.120). A desire to help may perpetuate certain beliefs among RCAs, such as the need to "give permission" to dying residents. This theme also suggests the potential usefulness of affirming to RCAs that they are doing a good job (Kaasalainen et al., 2007). Yet if institutional constraints to quality EOL care persist or increase, this may not only exacerbate moral distress (e.g., helplessness and frustration), but could erode a key mechanism available to RCAs for dealing with difficult emotions.

Stacey (2005) documents how home care aides identify constraints on their ability to do a good job (e.g. high demands, strain) while also constructing a sense of dignity and occupational reward (e.g., a sense of pride in doing relational or intimate work). The construction of dignity helps keep workers in these otherwise stigmatized, high demand, low-pay jobs. RCAs in the present study also cited sources of personal benefit from their work that can be viewed as helping them focus on the positive (such as living for the moment, accepting mortality, and the 'privilege' of EOL care).

Following a resident death, RCAs described having no choice but to focus on the task at hand and carry on with their work. Though some RCAs may find this a welcome form of emotional distraction, emotions may need to be processed after work, at home. In addition, for others, 'carrying on' may involve additional challenges that compound grief and require emotional labour (such as invoking the belief that one needs to 'stay strong' for others). It is as yet unknown how a lack of control over the expression of grief might affect RCA well-being.

Managing grief and difficult emotions related to both death and moral distress in EOL care is an often under-recognized part of RCA work. By applying an interpretive approach we documented several shared and socially constructed ideas that RCAs use to make sense of their EOL care experiences and manage their emotions. The findings from this analysis suggest the following possible recommendations: a) in some cases, to help RCAs problematize or reframe the assumption that death is a welcome relief from suffering and poor quality of life (as well as other beliefs, as needed); b) consider the potential for increases in moral distress in the current health care environment, and the implications of this for RCA wellbeing; c) integrate discussion of personal and emotional challenges of EOL care in RCA training; d) create greater opportunity for RCAs to express and deal with grief. Addressing these issues may help not only to promote RCA well-being but to improve the quality of EOL care in residential care settings.

REFERENCES

- Abbey, J., Froggatt, K.A., Parker, D., & Abbey, B. (2006). Palliative care in long-term care: A system in change. *International Journal of Older People Nursing*, 1, 56-63.
- Anderson, R.A., Ammarell, N., Bailey, D., Clon-Emeric, C., Corazzini, K.N., Lillie, M., et al. (2005). Nurse assistant mental models, sensemaking, care actions, and consequences for nursing home residents. *Qualitative Health Research*, 15(8), 1006-21.
- Anderson, K.A., & Gaugler, J.E. (2006). The grief experiences of certified nursing assistants: personal growth and complicated grief. *OMEGA: Journal of Death and Dying*, 54(4), 301-18.
- Atkinson, P., Coffey, C., & Delamont, S. (2003). *Key themes in Qualitative Research: Continuities and change*. Walnut Creek (CA): Alta Mira.
- Austin, W., Bergum, V., & Goldberg, L. (2003). Unable to answer the call of our patients: mental health nurses' experience of moral distress. *Nursing Inquiry*, 10(3), 177-83.
- Austin, W., Lemermeier, G., Goldberg, L., Bergum, V., & Johnson, M.S. (2005). Moral distress in healthcare practice: the situation of nurses. *HEC Forum*, 17(1), 33-68.
- Black, H.K., & Rubinstein, R.L. (2005). Direct care workers' response to dying and death in the nursing home: a case study. *The Journals of Gerontology*, 60(1), S3-S10.
- Black, H.K. (2004). Moral imagination in long-term care workers. *OMEGA: Journal of Death and Dying*, 49(4), 299-320.
- Casey, D., Murphy, K., Ni Leime, A., Larkin, P., Payne, S., Froggatt, K.A., et al. (2011). Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland. *Journal of Clinical Nursing*, 20, 1824-33.

- Davis, C.G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, 75(2), 561-74.
- Dein, S., & Qamar Abbas, S. (2005). The stresses of volunteering in a hospice: a qualitative study. *Palliative Medicine*, 19(1), 58-64.
- Enyert, G., & Burman, M.E. (1999). Qualitative study of self transcendence in caregivers of terminally ill patients. *American Journal of Hospice and Palliative Care*, 16, 455-62.
- Ersek, M., & Wilson, S.A. (2003). The challenges and opportunities in providing end-of-life care in nursing homes. *Journal of Palliative Medicine*, 6(1), 45-57.
- Ersek, M., Miller Kraybill, B., & Hansberry, J. (1999). Investigating the educational needs of licensed nursing staff and certified nursing assistants in nursing homes regarding end-of-life care. *American Journal of Hospice and Palliative Care*, 16(4), 573-82.
- Fillion, L., Duval, S., Dumont, S., Gagnon, P., Tremblay, I., Bairati, I., et al. (2009). Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care nurse. *Psycho-Oncology*, 18(12), 1300-10.
- Funk, L.M., & Stajduhar, K.I. (2009). Interviewing family caregivers: implications of the caregiving context for the research interview. *Qualitative Health Research*, 19(6), 859-67.
- Goodridge, D., Bond, J.B., Cameron, C., & McKean, E. (2005). End-of-life care in a nursing home: A study of family, nurse and healthcare aide perspectives. *International Journal of Palliative Nursing*, 11(5), 226-32.
- Gottlieb, B. H., & Wolfe, J. (2002). Coping with family caregiving to persons with dementia: A critical review. *Aging and Mental Health*, 6, 325-42.
- Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative Care*, 17(1), 30-6.

- Gubrium, J. F. & Holstein, J. A. (1997). *The New Language of Qualitative Method*. Oxford University Press, NY.
- Hanson, L.C., Henderson, M., & Menon, M. (2002). As individual as death itself: a focus group study of terminal care in nursing homes. *Journal of Palliative Medicine*, 5(1), 117-25.
- Hochschild, A. (1983). *The Managed Heart: Commercialization of human feeling*. Berkeley (CA): University of California Press.
- Holland, J.M., Currier, J.M., & Neimeyer, R.A. (2006). Meaning reconstruction in the first two years of bereavement: the role of sense-making and benefit finding. *OMEGA: Journal of Death and Dying*, 53(3), 175-91.
- Hopkinson, J.B., Hallett, C.E., & Luker, K.A. (2005). Everyday death: how do nurses cope with caring for dying people in the hospital? *International Journal of Nursing Studies*, 42(2), 125-33.
- Hudson P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing*, 10: 58–65.
- Kaaslainen, S., Brazil, K., Ploeg, J., & Martin, L.S. (2007). Nurses' perceptions around providing palliative care for long-term care residents with dementia. *Journal of Palliative Care*, 23(3), 173-80.
- Katz, J., Sidell, M., & Komaromy, C. (2000). Death in homes: bereavement needs of residents, relatives and staff. *International Journal of Palliative Nursing*, 6(6), 274-9.
- Katz, J., Sidell, M., & Komaromy, C. (2001). Dying in long-term care facilities: Support needs of other residents, relatives and staff. *American Journal of Hospice and Palliative Care*, 18(5), 321-6.
- Kayser-Jones, J., Schell, E., Lyons, W., Kris, A.E., Chan, J., & Beard, R.L. (2003). Factors that influence end-of-life care in nursing homes: The physical environment inadequate staffing, and lack of supervision. *The Gerontologist*, 43(2), 76-84.

- McClement, S., Wowchuk, S., & Klaasen, K. (2009). 'Caring as if it were my family': Health care aides' perspectives about expert care of the dying resident in a personal care home. *Palliative and Supportive Care*, 7(4), 449-57.
- Milberg, A., & Strang, P. (2003). Meaningfulness in palliative home care: an interview study of dying cancer patient's next of kin. *Palliative and Supportive Care*, 1(2), 171-80.
- Moss, M.S., Moss, S.Z., Rubinstein, R.L., & Black, H.K. (2003). The metaphor of 'family' in staff communication about dying and death. *The Journals of Gerontology*, 58(5), S290-96.
- Moss, M.S., Braunschweig, H., & Rubinstein, R.L. (2002). Terminal care for nursing home residents with dementia. *Alzheimer's Care Quarterly*, 3(3), 233-46.
- Österlind, J., Hansebo, G., Andersson, J., Ternestedt, B.M., & Hellstrom, I. (2011). A discourse of silence: professional carers reasoning about death and dying in nursing homes. *Ageing and Society*, 31(4), 529-44.
- Palan Lopez, R. (2007). Suffering and dying nursing home residents: nurses' perceptions of the role of family members. *Journal of Hospice and Palliative Nursing*, 9(3), 141-9.
- Rickerson, E.M., Somers, C., Allen, C.M., & Lewis, B. (2005). How well are we caring for caregivers? Prevalence of grief-related symptoms and need for bereavement support among long-term care staff. *Journal of Pain and Symptom Management*, 30(3), 227-33.
- Sinding, C., & Aronson, J. (2003). Exposing failures, unsettling accommodations: tensions in interview practice. *Qualitative Research*, 3(1), 95-117.
- Stacey, C.L. (2005). Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. *Sociology of Health and Illness*, 27(6), 831-54.
- Strang, V.R., & Koop, P.M. (2003). Factors which influence coping: home-based family caregiving of persons with advanced cancer. *Journal of Palliative Care*, 19, 107-14.

- Waskiewich, S., Funk, L.M., & Stajduhar, K.I. (*in press, 2012*) End of life in residential care from the perspective of care aides. *Canadian Journal on Aging*.
- Wilson, S.A., & Daley, B.J. (1998). Attachment/detachment: forces influencing care of the dying in long-term care. *Journal of Palliative Medicine*, 1(1), 21-35.
- Wong, W.K.T., & Ussher, J. (2009). Bereaved informal cancer carers making sense of their palliative care experiences at home. *Health and Social Care in the Community*, 17(3), 274-82.