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End of Life in Residential Care from the Perspective of Care Aides*

Shelly Waskiewich[†]

Laura M. Funk

Department of Sociology, University of Manitoba

Kelli I. Stajduhar

School of Nursing and Centre on Aging, University of Victoria

RÉSUMÉ

Nous avons examiné les caractéristiques contextuelles qui façonnent les soins de fin de vie (SFV) dans les établissements de soins pour bénéficiaires, en s'appuyant sur les perspectives de 11 **aidants résidents** (AR) dans un centre urbain canadien de l'Ouest. ARs décrivent les soins de fin de vie comme "offrant un confort," y compris le bien-être physique et émotionnel. Les inquiétudes au sujet des défis posés par le temps et la charge de travail ont dominé les comptes et ont généré la culpabilité, la tristesse et de la frustration. ARs ont essayé de "trouver le temps" en le prenant d'eux-mêmes ou les autres résidents, et en s'appuyant sur l'engagement des collègues et sur les familles. Les résultats soulignent l'importance du rôle d'AR (en particulier en offrant un confort émotionnel), mais faire appel à l'attention à l'interprétation de ce qui est impliqué dans ce travail, et à la définition du portée de la pratique et de la formation. Les résultats également réitère l'importance, entre aidants résidents canadiens, des charges de travail adéquates pour faciliter les soins de fin de vie de qualité, et soulève des préoccupations au sujet des contraintes et comment elles forment la pratique de soins de fin de vie et les significations qui infusent une telle pratique.

ABSTRACT

We explored contextual features shaping end-of-life (EOL) care in residential care facilities by drawing on the perspectives of 11 resident care aides (RCAs) in one Western Canadian urban centre. RCAs characterized EOL care as "providing comfort", including physical and emotional comfort. Concerns with time and workload challenges dominated accounts and generated guilt, sadness, and frustration. RCAs tried to "find the time" by taking it from themselves or other residents, and by relying on the commitment of co-workers and on families. Findings emphasize the importance of the RCA role (particularly in emotional comfort), yet call for attention to interpretations of what is involved in this work, and to definitions of scopes of practice and training requirements. Findings reiterate the importance, among Canadian RCAs, of appropriate workloads to facilitate quality EOL care, and raise concerns about how time constraints shape EOL care practice and the meanings infusing this practice.

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Correspondence and requests for offprints should be sent to / La correspondance et les demandes de tirés-à-part doivent être adressées à:

Laura M. Funk, Ph.D.

Department of Sociology

University of Manitoba

Isbister Building

307-183 Dafoe Road

Winnipeg, Manitoba R3T 2N2

(Laura.Funk@ad.umanitoba.ca)

The context of residential care is changing in Canada and similar industrialized countries. Older adults are admitted to these facilities in advanced stages of illness, and their care needs are both extensive and intensive (Wowchuk, McClement, & Bond, 2006). For instance, approximately 87 per cent of care facility residents have cognitive impairment or dementia, and many of them die in this setting (Graham et al., 1997). Care for residents with either dementia or non-malignant disease can involve responding to unpredictable trajectories of "slow decline with periodic crises and less-defined terminal phases" (Hall, Schroder, & Weaver, 2002, p. 504).

As care home residents near the end of life, their care needs change, which may require more intensive resources, including "more aggressive pain and symptom management and emotional support" (Rice, Coleman, Fish, Levy, & Kutner, 2004, p. 669). The traditional focus of residential care has been on "doing everything to keep people alive" (Abbey, Froggatt, Parker, & Abbey, 2006, p. 59) and maintaining function and independence (Wetle, Shield, Teno, Miller, & Welch, 2005; Wowchuk et al., 2006). A philosophical shift to a palliative approach, therefore, has been limited. Yet such palliative care overall has been described as "suboptimal" in residential care facilities (Kaaslaainen, Brazil, Ploeg, & Martin, 2007), particularly for persons with dementia. Inadequacies of end-of-life (EOL) care in this setting include deficiencies in basic care, hygiene, and ingestion of foods and fluids, as well as under-recognition of discomfort among persons with dementia (Harris, 2007; Kayser-Jones et al., 2003; Moss, Braunschweig, & Rubinstein, 2002). As such facilities will increasingly provide care to dying persons (Wowchuk et al., 2006), it is essential to improve the quality of this care.

The majority of direct, physical, and front-line care for care facility residents in Canada and elsewhere is provided by paid resident care aides (RCAs) who generally have low levels of training (Ersek, Kraybill, & Hansberry, 1999). In Canada, RCAs do not hold professional licences and typically have a college certificate and/or receive on-the-job training. RCAs – who provide care on a 24-hour basis, have extensive experience providing direct resident care, and contribute to the quality of EOL care – may work under conditions of (a) inadequate staffing and supervision (Kayser-Jones et al., 2003), (b) high turnover, (c) low morale (Quadagno & Stahl, 2003), and (d) heavy workloads (Kayser-Jones, 2002). These issues can exacerbate the challenges of providing care to dying residents with complex and diverse care needs.

Applied research in health services often involves talking with service providers directly about their practice

experiences. Drawing on RCAs' experiential knowledge of their practice contexts and the complexities of providing EOL care in residential care settings can enhance our understanding of how EOL care is delivered; in turn, this could inform the development of strategies to improve the quality of EOL care. This qualitative study explored features shaping the provision of EOL care to care facility residents by drawing on RCA perspectives.

Literature Review

EOL care involves addressing physical care and symptom management, emotional and spiritual support, advance care planning, environmental support, and the needs of families. Although specific clinical and practice challenges such as pain and symptom management exist, some research has begun to identify broader features shaping the provision of EOL care in nursing homes or residential care settings.

One of the challenges faced by care facility staff is determining when a palliative approach to care is appropriate, particularly with respect to chronic and/or non-malignant illnesses with less predictable trajectories. Ongoing symptom assessment is important to quality EOL care and is related not only to staff knowledge of the resident but also to the availability of diagnostic test results (Goodridge, Bond, Cameron, & McKean, 2005) and to challenges assessing diagnostic status and pain among persons with dementia (Hanson, Henderson, & Menon, 2002; Moss et al., 2002). Accordingly, client population characteristics affect the ability of staff to identify when residents could benefit from a palliative approach (Volicer, 2002).

There may also be a lack of consensus in a facility regarding what constitutes palliative care (Brazil et al., 2006) and resistance to accepting such an approach (Blasi, Hurley, & Volicer, 2002; Hanson et al., 2002; Travis et al., 2002). Broader contributing factors to such resistance can include the traditional organizational culture of treatment, rehabilitation, and life prolongation in residential care (Froggatt, 2001; Watson, Hockley, & Dewar, 2006).

Greater specialized EOL care training for care staff is a common recommendation in existing literature (e.g., Ersek et al., 1999; Raudonis, Kyba, & Kinsey, 2002; Rice et al., 2004; Zimmerman, Sloane, Hanson, Mitchell, & Shy, 2003). Some staff lack knowledge about the dying process and palliative care provision (Brazil et al., 2006; Ersek & Wilson, 2003; Hanson et al., 2002; Nochomovitz et al., 2010; Watson et al., 2006). Moreover, they may also lack skills in recognizing when residents are on a dying trajectory (Brazil et al., 2006).

and in communicating with residents and their families (Hanson et al., 2002). Institutions can face resource challenges in addressing staff educational needs (Brazil & Vohra, 2005) and providing adequate supervision (Kayser-Jones et al., 2003).

Staff members' knowledge about the personalities and preferences of individual residents also affects their ability to provide individualized care, which is an important component of EOL care (Goodridge et al., 2005; Hanson et al., 2002). This knowledge is affected by the staff member's skill and by institutional features and care practices that affect staff-resident relationships.

An environment that facilitates a "good death" is characterized by privacy, a peaceful atmosphere, and convenience for visiting family members (Brazil et al., 2004). Yet the physical space in some facilities (e.g., multi-bed rooms) lacks these qualities (Kayser-Jones et al., 2003) and may be noisy, crowded, or have an "institutional" atmosphere. A lack of specialized equipment in facilities, such as pain pumps, can be another barrier to the provision of quality EOL care (Brazil et al., 2006).

Consistently identified challenges facing EOL care in residential care facilities include staffing ratios, heavy workloads, and time constraints (Brazil et al., 2006; Brazil et al., 2004; Hanson et al., 2002; Kayser-Jones et al., 2003; Munn et al., 2008; Rice et al., 2004; Zimmerman et al., 2003). In one study (Temkin-Greener et al., 2009), facilities with higher care aide staffing ratios scored higher on measures of EOL care processes. Workloads are affected by the increasingly complex and high needs of resident populations (Chen, Chan, Kiely, Morris, & Mitchell, 2007; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), the particular needs of those at end of life (Brazil et al., 2006), and more broadly by the predominance of a business model in residential care facility operations (Brazil et al., 2004). High workloads may also be associated with high turnover, low morale, and high job dissatisfaction, further affecting workers' ability and motivation to provide EOL care (Quadagno & Stahl, 2003; Kayser-Jones, 2002).

Teamwork, good communication, and coordination have been identified as contributing to better-quality EOL care in residential care (Goodridge et al., 2005; Hanson et al., 2002; Travis et al., 2002). Quality assurance or monitoring mechanisms, practice guidelines, and an organizational emphasis on EOL staff education can also facilitate quality EOL care (Brazil et al., 2006, Temkin-Greener et al., 2009). Supportive regulatory and reimbursement mechanisms (Ersek & Wilson, 2003) are also important, including (in Canada) appropriate reimbursement from health insurance programs

for palliative care (Brazil et al., 2006). In one study (Moss et al., 2002), only half of participating facilities had palliative care practice policies. Staff in some residential care settings may be expected to provide complex EOL care in the absence of policies that support care quality.

The majority of research on EOL care in residential care settings has been conducted in the United States. Few studies have focused exclusively on the perspectives of RCAs; those that do have typically collected data through focus groups (Brazil et al., 2004; Ersek, et al., 1999; Kaasalainen et al., 2007). RCAs' viewpoints are important because they provide the majority of direct, primary care in residential care settings, yet their perspectives tend to be marginalized, perhaps due to the low occupational hierarchy position of RCAs. RCAs have important contributions to make in helping us to better understand the barriers they experience in providing quality EOL care in these environments. The research question that our study addressed is: What do RCAs experience as shaping their provision of EOL care in residential care settings?

Methods

Participants in this study included certified RCAs who had worked full time for at least one year in a residential care facility and had experience providing EOL care to residents. RCAs were required to be at least 19 years of age, speak fluent English, and reside in an urban centre in Western Canada. The director of residential services with the regional health authority facilitated recruitment. A presentation was given by the first author at a meeting of residential care managers in the local health agency, outlining the study purpose and asking for permission to recruit RCAs within the facilities that they managed. Three managers volunteered their facilities as study sites, one of which had a special care unit for people with dementia. Presentations at staff meetings were conducted in these three facilities, recruitment information was posted on facility bulletin boards, and letters of invitation for participation were left on the units. The invitation asked RCAs – who (a) provided care to a resident who had died at their place of work and (b) were willing to participate in the study – to contact the researchers directly.

Eleven RCAs participated in individual, face-to-face, qualitative interviews. Informed consent was obtained in writing, and interviews occurred either away from the facility or as privately as possible within the facility. Guiding questions were used, such as: "Can you tell me what it is like for you to provide care to residents nearing death?"; "What do you think quality end-of-life care is?"; and "What are some challenges

you face providing EOL care?" Participants were asked to elaborate with examples and descriptions, as well as recommendations for improving EOL care. Interviews, which were audio-recorded with participant consent, were transcribed verbatim. We also collected demographic information to describe the sample.

This study utilized the applied qualitative approach of "interpretive description" which is suitable for examining clinical phenomena (Thorne, Kirkham, & MacDonald-Emes, 1997) to generate knowledge that can inform practice. This approach acknowledges the constructed and contextual nature of an individual's experience while at the same time acknowledging that shared realities exist within these individual experiences (Thorne et al., 1997). Interpretive description aims to move qualitative inquiry beyond the level of description to a more abstracted form of interpretation in order to guide and inform clinical understanding and disciplinary thought (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). The analysis focused on exploring emerging and recurrent themes, and similarities and differences among them. An initial index with themes was developed and applied, and data were sorted and grouped within similar themes, leading to the development of comparisons and further refinement of subthemes.

After first examining RCAs' interpretations of quality EOL care, we focused our analysis on thematic identification of contextual features shaping this care. To enhance rigor and account for any potential investigator bias, we asked almost half of the participants to evaluate the emerging analysis. Additionally, two academic researchers performed an independent analysis of the transcripts.

Findings

Sample Description

Seven female and four male RCAs participated. Their average age was 48 years, ranging between 23 and 61 years. Five RCAs described themselves as married or cohabiting; two, widowed; three, divorced, and one, never married. 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 some formal training in palliative or EOL care, ranging from content 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 2 to 45, with an average of 22.5 years.

Interpreting the Provision of Quality Care at EOL

The dominant word that participants used to describe good EOL care was "comfort", as in: "it's their [residents'] end of life and you want [them] to be as comfortable as they can be"; and "make sure that they're not having any discomfort of mind or body, and if you can do that, then you've done your job." Less common descriptors of good EOL care, sometimes used synonymously with *comfort*, were "clean", "dignity", "gentleness", "compassion", and "respect". Participants also frequently spoke about caring for dying persons the way they themselves would want to be cared for at their end of life (or for a family member in similar circumstances). For instance, it was important to "put yourself in their spot" or "treat them like they're your own mother and father". In defining good-quality EOL care, RCAs described their role as promoting physical and emotional comfort and, to a lesser extent, comforting families.

Physical Comfort

Participants described addressing dying residents' physical comfort primarily through being gentle as they provided care, and by frequently checking on, assessing, and tending to physical needs. One RCA spoke about keeping bedcovers loose because "[residents'] skin quite often is very sore". Others referred to how body temperature can fluctuate, requiring that RCAs at times apply a cold cloth to a resident's forehead, or open a window, or remove blankets. Several RCAs referred to the importance of frequent mouth care, of turning and repositioning the residents in bed, and of extra efforts to keep residents' bodies, clothes, and sheets clean. One RCA explained that she tries to keep fresh gowns on dying residents because of an unpleasant smell associated with the dying process. Other participants described applying lotion to the resident's body, massaging residents, combing their hair, and frequently offering them food.

In turning and handling dying residents, RCAs emphasized being physically gentle to avoid causing additional and unnecessary pain. One RCA described poor EOL care as being abrupt in turning residents, or letting their limbs "flop about", as opposed to turning them "all in one roll". The RCA described this not only as poor care but as undignified (treating bodies "as a piece of meat"). Another RCA stated: "You don't want to rush through personal care with a dying person, like you would normally with other residents: instead, you can take more time so you don't cause them more pain." Dignity as well as comfort was mentioned by some participants – for instance, with respect to handling residents' bodies (e.g., not leaving residents' bodies exposed, or asking family members to leave while RCAs perform personal care).

Study participants did not speak extensively about pain even when asked directly. To address pain, RCAs focused on activities they normally can do to promote physical or emotional comfort. Less often (and usually when asked), they spoke of their role in alerting the registered nurse (RN) to the need for medication. One RCA spoke of trying to distract dying persons' attention from their bodies or pain through strategies similar to "hypnotherapy" and helping them emotionally process the impending death. He believed that morphine could lead to "overdosing" and inducing death. Although other RCAs held similar beliefs about morphine "hastening the end" (and some believed it was used by RNs to facilitate death), most thought medications should be given to alleviate pain.

Emotional Comfort

Study participants focused to a great extent on the emotional comfort they provide dying residents through (a) offering emotional support and reassurance, (b) providing companionship, and (c) creating a peaceful atmosphere.

Participants described ways in which they provide emotional support and reassurance to dying residents. As RCAs, they were conscious of how the awareness of imminent death – as well as the multiple losses involved in aging and (for some) the experience of cognitive impairment – may generate fear, anxiety, and uncertainty for residents. RCAs sought to calm and reassure dying persons – for instance, through their own facial expressions and eye contact; talking to residents and conveying care for them; repeating words like "safe" or "calm;" using humour; or by simply listening to them. One RCA said: "I explain what I'm doing and who I am and use their name." Another advised: "Let them know that you're there and that you care." Talking to the resident was considered important not just for comfort, but also to promote dignity through keeping the resident informed.

Participants described helping residents accept their imminent death, alleviating their fears, and providing comfort. This could involve making sure spiritual needs were addressed (arranging for a pastor or last rites). As one RCA declared: "The whole purpose of religion is just to help us deal with the hereafter." This same RCA often described one of his personal experiences (which occurred within the context of a dream) to residents, to convey his own belief that "all those [who] left before us are there waiting" after we die, to help "make it [death] a little more palatable ... to actually have something to look forward to."

Rooted in a common belief that dying persons need to be "given permission" from others to die, participants spoke of comforting dying residents by telling them

that it is "okay for you to pass away", "go towards the light", "you can go now", or even telling them that "we'll help support their family when they're gone." Two RCAs implied causal connections between these kinds of communications and residents' deaths, as if they had helped residents make the transition. Participants also discussed how resolving important family and emotional issues and saying goodbye could be helpful – for instance, so the spirit does not struggle "to try and stay in this world" (e.g., reflected in a body that appears to struggle physically). Some RCAs try to encourage the resident to talk about and then let go of feelings of guilt, shame, or regret in their lives. One RCA described his efforts in this regard as "trying to empty the garbage can so they can go in peace". Another RCA spoke of actively trying to rebuild the bond between a dying mother and her son:

I said, 'All he needs to hear is you to say that you love him.' And she did, and he turned, came back in the room and stayed for hours, and they fixed whatever was wrong. She passed shortly after, within a week, and it was just so neat and gratifying to know that you maybe had helped a little bit.

Other participants spoke of reassuring residents that their family members would manage without them, or of helping them "clear the air" or "make good" on past mistakes or issues (e.g., apologizing to family members).

Another key way in which participants described providing emotional comfort for dying residents was through companionship: sitting with them, holding their hand, or reading to them. "Being with" was commonly equated with offering quality EOL care, and as communicating to the resident that they are cared about, which can bring comfort. Poor care was described as leaving a dying resident alone and lonely. Most RCAs believed that dying persons should not be left for long on their own and should not die alone in their rooms; as a result, RCAs try to spend as much time with dying residents as possible within workload constraints, and expressed disappointment or guilt when having to leave them alone for extended periods.

A few RCAs, however, wondered whether some dying residents may actually prefer being alone. A concern with leaving dying persons alone meant that residents without family were of particular concern to RCAs. One RCA was also more concerned with leaving cognitively alert residents alone:

I feel that they know that they're all alone and that's when I want to spend more time with them ... I don't really go out of my way to [sit with dying residents with dementia] because I don't think that it would make a difference.

Participants also described providing emotional comfort through ensuring a peaceful atmosphere: talking softly, not rushing or making loud noises, keeping a door shut, opening windows for fresh air, and arranging for a clean and tidy room. Having appropriate lighting – not too bright or too low – was also important. Low noise was seen as ideal, but RCAs said complete quiet should be avoided – for instance, to reduce feelings of isolation: “One lady I remember telling me, ‘you know how many people walk past this room and I can hear them walking past, why does no one come in?’ It just breaks my heart.” Individualized touches were described as helpful (and providing familiarity for residents with dementia), as with one RCA who described putting the resident’s prized possessions where they could be seen or touched, or other RCAs who spoke about playing residents’ preferred type of music.

Comforting the Family

RCAs described helping and comforting families through emotional and environmental support, and by informing and involving them. They described getting to know families, addressing their needs (e.g., offering coffee or soup; blankets), encouraging them to make themselves “at home”, and reassuring them that their family member would be well looked after. Some participants described talking with families about the resident or their care, providing information or answering their questions; letting them talk about their family member or emotions; and providing emotional support by listening. One RCA also noted simply dropping in to a resident’s room to check up on them, and in doing so to “be there enough so that they know that someone cares.” Helping family members accept the imminent death was important, as in the following participant comment: “I try to make them feel as comfortable as possible. I try to let them know that this is okay, that this is all part of life.”

Helping family members after the death of the resident was not discussed extensively, although some participants mentioned the importance of giving the family time to grieve with the body, as well as of providing advice (e.g., funeral planning; strategies for coping with grief). One RCA also referred to comforting bereaved family members by telling them “it was a pleasure taking care of their mother”.

Features Shaping the Delivery of Quality EOL Care in Residential Care Settings

Participants described themselves as committed to delivering good-quality EOL care, but spoke of several interrelated features that affected their ability and capacity to provide this care in residential care facilities.

Time and Workload

Issues of time and workload predominated participant accounts of factors shaping their ability to provide quality EOL care in residential care environments. Their comments about a lack of sufficient time to care for dying residents generated feelings of guilt, sadness, and frustration, and informed their desire for more help in providing such care. Although RCAs emphasized that spending time with dying residents was an important component of EOL care (and one which they can provide), they faced time challenges in doing so. One RCA, for instance, described how she had provided some care to a dying resident in the morning but

then I’m busy with everybody else ... and ... he’s not saying anything [e.g., asking for help] because he’s not in good health. And 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.

Most RCAs believed time constraints have increased over the years, due to the more complex care needs of contemporary resident populations; greater use of, and more complex, medical technologies; additional tasks in their workloads; and increasing budgetary constraints in tandem with staffing reductions. RCAs also observed differences, however, in available time between different facilities, shifts, and particular days or situations (e.g., flu virus, short-staffed days). One RCA reflected that, more recently, being provided pagers that freed them from the nursing station enabled RCAs to spend more time to check on dying residents.

Time challenges can create a context in which the delivery of quality EOL care is more discretionary and dependent on the commitment of individual RCAs. One RCA noted that “If you have a person dying in your section, it’s *entirely* up to that RCA’s discretion as to how much time they’re going to spend with that person.” In this situation, the dilemma in whether RCAs are motivated to “put in that extra mile” or just “do their job” becomes more salient; participants suggested the choice of which option they pursue depends on their compassion and closeness to particular residents. One RCA, although maintaining that all residents should be treated the same way, added that

There are some that you want to sit with or spend a little time with, so I always try to squeeze a few minutes ... You don’t always have the time but ... [you try to give it to] the special ones that you’ve really sort of bonded with.

Issues of time and workload – as well as being the most frequently mentioned challenge in providing EOL care – infused participants’ descriptions of features

facilitating EOL care: contributing one's own unpaid time, prioritizing care between residents, and relying on "a good team" as well as on family members and volunteers.

Finding the Time: Taking It Away from Oneself or Other Residents

Motivated by their desire to provide quality EOL care, yet constrained in available time, RCAs described how they try to find the time to spend with dying residents. Some skip their coffee breaks, or spend their coffee breaks with the dying resident. Others rush through other aspects of their work to gain extra minutes to sit with the dying person. Yet this prioritization usually entails taking time away from other residents on the RCA's caseload, as expressed by these comments: "I feel that I'm neglecting somebody else to be there for them"; "Sometimes I've literally cut down on the care that I've given the next person because I wanted to stay with the person who's passing away, longer"; and "You steal it from other people that are living". Another RCA explained how extra time for the dying person means someone else is not getting their "proper time" because their care has been rushed.

Finding the Time: Help from Co-workers

In describing what helps them provide quality EOL care under time constraints, participants frequently referred to teamwork and collaboration, and the commitment of other staff members to providing quality EOL care. A good team was described as one in which RCAs help each other out, covering for each other when needed, and sharing responsibility. Participants referred to "working as a team": they appreciated co-workers who helped them directly with dying residents or indirectly through covering for them with other residents. For instance, RCAs spoke of how it is helpful to have another RCA present when turning a dying resident in bed (one described this as the standard for EOL care in their facility). Many RCAs would ask co-workers to check in on a dying resident and referred to unspoken and unwritten agreements between staff in this regard, as in: "We're a pretty good team up here. Everybody cares for the person that's dying."

Teamwork as shared responsibility requires that co-workers think broadly and be willing to help a resident regardless of whether the resident is on their unit or part of their caseload. This is facilitated by bonds between staff members who know each other (and the facility) well. It is also facilitated when team members share a common commitment to quality EOL care and shared responsibility. One RCA noted: "Maybe a key point is to have [the responsibility] as a team instead

of for one person to be looking after that person." Shared responsibility is also facilitated by mutual exchanges of help between RCAs.

Some RCAs observed that team quality and commitment to shared responsibility for dying residents "depends on where you're working and who you're working with". Participants often lamented the lack of commitment to EOL care among RCAs who were burned out, had low morale, lower standards of care, and were inexperienced or uncomfortable with death. Such staff might be unwilling to cover for them or take on extra tasks to help them care for dying residents, instead strongly adhering to their standard job descriptions or assigned resident workloads. Such "personalities" were described as elements that weaken the team.

Finding the Time: Help from Families and Volunteers

Earlier we described how participants spoke of comforting families (e.g., as part of the unit of care). In the context of workload and time restrictions, however, families are simultaneously viewed as providers of EOL care and as substitutes for RCA care. One RCA, describing heavy workloads, stated: "[the workload] doesn't allow the time for any one person to stay with that [dying] person, so we count on family coming in to take care of their family." Examples in which RCAs characterized families as facilitators of EOL care included: "We couldn't pay them enough for those little bits that they do so we can get our work done"; "It's a big help. You don't feel like you don't have time for this person because there's somebody there"; and "When family's there, I feel a little less guilt because I know somebody's with [the dying resident]". Another RCA stated: "It makes care much easier, because it's almost like taking away one of your residents" from their workload. One RCA cautioned, however, against getting accustomed to family visiting, because "then when [family] are not there, it's almost double the hit" – not only does the RCA's workload increase, but the resident has become accustomed to the frequent attention and calls more often for help. Help from families aside, RCAs expressed more concern for their capacity to respond to the needs of dying residents who did not have family members available or visiting.

To a lesser extent, RCAs described ways in which families can pose a challenge to the provision of good EOL care. In some cases, families visit so often that RCAs find it difficult to interrupt or disturb them in order to provide resident care. In other cases, RCAs spend time "appeasing" families who become upset over "little things" (e.g., a missing sock). Lastly, RCAs viewed families as a barrier to good-quality EOL care when they are stubborn about how care should be

performed (e.g., refusing pain medication for the resident) or when they fight among themselves (thereby stressing the resident).

Some RCAs described how they encouraged families to be involved – to hold the resident's hand, comb their hair, rub their feet or apply lotion, read to them, or otherwise help with personal care (e.g., mouth care). This involvement was described in part as about helping families, who may benefit from such involvement with their dying family member. But it is also in part about helping RCAs to provide care, and thus is mutually beneficial.

A desire for paying more attention to dying residents who lack families also informed participants' recommendations for greater use of volunteers to sit with dying residents. For instance: "Between 2:00 and 3:00 I don't have to go check on her because the volunteer will be in there keeping her comfortable." Several RCAs mentioned that their facility had such a volunteer program in the past but that this stopped when the facility underwent a change in governance, and they were uncertain as to why (perhaps a loss of funding for a coordinator, or a lack of willing volunteers, or a lack of uptake of the program).

Scopes of Practice and Institutional Policies

Particularly when referring to pain management, RCAs referred to EOL care challenges related to scopes of practice. RCAs' ability to address some aspects of EOL care (especially pain) was limited, and this generated a sense of helplessness, as reflected in this comment: "There's not much else that I can do other than [normal comfort measures], unfortunately." This was exacerbated in situations involving a lack of availability of doctors, or timely approval by doctors (who must sign off on RN medication requests), or when RNs themselves did not respond quickly (or who questioned the RCA's pain assessment). One RCA noted: "You really wish you could almost administer [morphine] yourself because at least the person's going to be out of pain." Other RCAs referred to how the boundaries of their practice imposed limitations on their abilities to help or inform families, or to arrange for volunteers to sit with dying residents.

One RCA further spoke about the inflexibility of certain institutional policies (restrictions, limitations or prohibitions as to diet, flowers, alcohol, or pet visits) as a barrier to EOL care, yet noted how they sometimes "work around" or "cheat" on such policies if they believe the policy could be detrimental to the resident's well-being. Another RCA noted how family participation in care provision was discouraged at her facility (unless families agree to take full responsibility, in writing) "because we have a

standard that we're supposed to follow and if the families get injured during care there could be legal issues." Another RCA referred to policy change: their facility used to appoint one RCA just to sit with dying residents, but this policy was eliminated. Policies can also facilitate EOL care – for instance, where there is a policy that two RCAs assist with moving a dying resident.

Physical Environments: The Palliative Room

Having a designated room for dying residents provides privacy, viewed as an aspect of quality EOL care, and facilitates the RCA's ability to provide direct care to the dying person. A few RCAs, however, wondered whether some residents might actually prefer to stay in their more familiar room, and were concerned about the impact of the stigma associated with moving to the palliative room. Although many facilities had a palliative room of some form, the spaces varied in quality. High-quality palliative rooms were characterized as bright (with adjustable lighting), colourful, quiet and peaceful, clean and uncluttered, having a sink or bathroom, stereo or radio, appealing windows and curtains, sufficient space for visiting family, and a place to set up a resident's personal things within view. Ideally, supplies should also be available (e.g., good lotion, powders for skin). RCAs also tended to desire a room designated just for dying residents as opposed to a multi-functional one (e.g., computer use and storage). Furthermore, when the room was physically located at the end or exterior of a unit, the distance was felt to exacerbate time challenges in providing EOL care. Finally, two participants mentioned the potential benefit of a second, private room where family members could converse separately from the patient, (e.g., "with some snacks and drinks for them to go to and have a breather").

Training, Education, and Experience

The RCAs speculated that some of their co-workers might not know how to provide EOL care, whether because of a lack of knowledge, lack of experience working with dying persons, or personal discomfort with dying. Their recommendations centered on the care facilities' providing ongoing training on EOL issues and care (such as through in-services), beyond that which RCAs receive in their certification. As one RCA stated, training "shouldn't always be on your day off and you shouldn't have to fight to want to be paid to learn." Such training could serve as "reminders" and provide current practical information; as one RCA expressed it, "If there is new material out there, I'd like the opportunity to know about it." However, RCAs also believed such training could help change RCA attitudes towards EOL care, as in:

It needs to be drilled into some of the employees' heads: if that was you lying on that bed, what are you going to want? ... You need to give them proper care right to the end ... be a little more caring right up to the end.

Another RCA likewise lamented that students did not appear to be taught the value of teamwork, shared responsibility, and "give and take" between co-workers. Other RCAs emphasized experiential learning, whether it was acquired on-the-job or through personal experience (outside of work) with death, which could provide knowledge about the process and comfort with working with the dying, as well as enhance compassion for the dying: "After someone's had a relative die or something, they always seem to come back a little bit changed ... they're just a little more caring, because they've gone through it themselves."

Practice Challenges and Knowing the Resident

Finally, although practice-related challenges were not a dominant theme, RCAs at times referred to such challenges in particular situations as influencing their ability to provide EOL care. These included individual resident behaviours (e.g., aggressive behaviours of persons with dementia) and unpredictable illness trajectories, as well as pain management challenges. Assessing resident needs (especially when residents cannot communicate) can also be a practice challenge for RCAs, but this is facilitated by knowing the resident. For instance, RCAs might assess physical comfort and pain through the resident's body language, movements, or facial and eye expressions. Some study participants implied that this kind of assessment is easier if they already know that resident well. Others likewise spoke of the importance of individualized knowledge: "You've got to know that resident a little bit to know – they did like rock and roll, or they liked this or that or ... So the challenge is to know what's going to make them feel comfortable." RCAs can also learn from families what might make the resident comfortable, although as one RCA noted, the family might have erroneous perceptions. Finally, RCAs can also check the resident's case files for information, or talk with co-workers who might know the resident better.

Discussion and Conclusions

This qualitative study is one of the first in Canada to draw directly on the perspectives of individual RCAs in exploring features that shape the provision of EOL care in residential care settings. Generalized conclusions are limited given the small sample size, and quite likely other features exist that were not mentioned by these RCAs but which influence EOL care delivery. Nonetheless, those features the participants identified

are arguably the most directly relevant to their own work in the provision of frontline EOL care and stem from their experiential, often marginalized, perspectives. The care delivery features they identified represent those that RCAs experience most acutely and that have the greatest potential effect on their job satisfaction.

RCAs in this study heavily emphasized the importance of emotional comfort in EOL care provision. It is possible that some of this emphasis stems from RCAs' own needs for closure in their relationships with residents, although indeed, the "attachment" between staff and residents is regarded by many as key to the quality of EOL care provision (Wilson & Daley, 1998).

A primary tension was identified between RCAs' wanting to spend time with the dying resident, yet struggling to find this time in the current context of their workload. Resources, staffing, and time have been well-documented as a challenge for quality EOL care in residential care facilities in other research; our study not only confirms this in a sample of Canadian RCAs but also demonstrates how this feature informs RCAs' understanding of what constitute *facilitators* of EOL care. This study further identifies how time and workload constraints generate difficult feelings for RCAs, who respond by seeking to find the time through cutting into their own work time, taking the time from other residents on their caseload, sharing responsibility with co-workers, or relying on the unpaid contributions and time of families and volunteers. In the context of increasingly constrained residential care systems, these findings raise particular concerns about (a) the potential for widening inequities of care between dying and chronically ill residents; (b) a growing tendency to view family members as substitutes for (rather than as part of the care spectrum that includes) RCA care; and (c) viewing the generosity of volunteers as a source of "free labour" that replaces rather than supplements formal services.

RCAs who volunteered for this study appeared to openly embrace and accept a palliative approach, and did not tend to apply a medicalized approach to death. However, some of their specific beliefs about death, dying, and EOL care should be explored further in research with other RCAs, and potentially problematized. This includes, for instance, beliefs that dying persons should not be alone, should be in a specially designated room, and should receive greater care and attention than other residents. The latter belief in particular could be explored, through asking: In what ways is good EOL care different from good resident care in these settings, and why? Another belief that could be examined in greater depth is the belief that dying residents need to be "given permission" to die.

The origins and functions of this shared “conventional wisdom” among RCAs and other health care providers should be probed in more depth.

Contrary to some of the literature in which barriers to EOL care is identified, participants in this study expressed no concern with their own ability to detect the approach of a resident’s end of life, or a need for a palliative approach. Though it is possible that this self-selecting sample of RCAs may have greater knowledge of EOL care, we do not know the accuracy of their assessments. It is also possible that some RCAs de-emphasized any possible gaps in their knowledge of EOL care, in order to present themselves as competent and confident in the interview interaction. RCAs’ assessments of their expertise could be explored in future research.

This study is unique in contextualizing the interpretation of the meaning of “teamwork” in the provision of EOL care in residential care settings. Given the overarching challenge of both time and workload constraints, RCAs promoted a view of teamwork that helped them provide the best EOL care possible within these constraints. They tended to characterize teamwork as shared responsibility and commitment between co-workers (primarily other RCAs). From this perspective, a good team member is one who believes in “helping each other out” even if this means going beyond the normally expected boundaries of a given RCA’s caseload. Participants who did not follow this approach were criticized by other participants as having a weaker commitment to EOL care. Ironically, however, when participants spoke about features influencing their personal ability to provide quality EOL care, they acknowledged their own boundaries of practice as a legitimate constraint.

Further exploration is needed into the ways in which RCAs interpret and define the boundaries and scope of their practice in providing EOL care, as there appears to be considerable variation in the kinds of activities considered to be part of this role (e.g., with respect to understandings of the provision of emotional support, as well as care for and communication with family). If practice guidelines are not available, they should be developed (Brazil et al., 2006). The potential might well exist for an expanded role for RCAs in EOL care provision; however, this needs to be accompanied by appropriate levels of education, as well as training in self-awareness and critical reflection (i.e., about personal assumptions and beliefs). Indeed, this training is warranted simply by the fact that RCAs are heavily involved in the provision of direct care to dying residents, and will increasingly be so in the future. Interestingly, the study participants, although indicating the importance of training, emphasized that training is essential not only in practical knowledge

and skills, but also in the aspects of affective or attitudinal learning.

Considered together with findings from other studies in this research area, the results of our study can inform improvements to the practice of EOL care by RCAs in residential care settings. First, the findings emphasize the importance of the RCA role, particularly in providing emotional comfort to dying residents; however, they call for greater attention (in practice, management, and training) to the interpretation of what the work involves and the justification of these tasks, as well as to defining the associated scopes of practice and training requirements. Second, the findings reiterate the overarching importance, for Canadian RCAs, of maintaining appropriate workloads in order to facilitate high-quality EOL care; these findings raise particular concerns about how the practice of EOL care, and the meanings infusing this practice (such as teamwork), may be shaped as a result of time constraints. Directed consideration to addressing these two primary concerns in RCA practice, management and training may yield improvements not only in the quality of EOL care in residential care facilities, but also to the quality of RCA work experiences and satisfaction.

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