Sources of moral distress for nursing staff providing care to residents with dementia

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Abstract

The World Health Organization estimates the number of people living with dementia at approximately 35.6 million; they project a doubling of this number by 2030 and tripling by 2050. Although the majority of people living with a dementia live in the community, residential facility care by nursing care providers is a significant component of the dementia journey in most countries. Research has also shown that caring for persons with dementia can be emotionally, physically, and ethically challenging, and that turnover in nursing staff in residential care settings tends to be high. Moral distress has been explored in a variety of settings where nurses provide acute or intensive care. The concept, however, has not previously been explored in residential facility care settings, particularly as related to the care of persons with dementia. In this paper, we explore moral distress in these settings, using Nathaniel's definition of moral distress: the pain or anguish affecting the mind, body, or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, makes a moral judgment about the correct action and yet, as a result of real or perceived constraints, cannot do what is thought to be right. We report findings from a qualitative study of moral distress in a single health region in a Canadian province. Our aim in this paper is to share findings that elucidate the sources of moral distress experienced by nursing care providers in the residential care of people living with dementia.

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Introduction

In 2012, the World Health Organization estimated that the number of people living with dementia worldwide was approximately 35.6 million; they projected a doubling of this number by 2030 and tripling by 2050 (World Health Organization, 2012). Although the majority of people living with a dementia live in the community, residential facility care by nursing providers is a significant component of the dementia journey in most countries (World Health Organization, 2012). In fact, literature from around the world confirms that of those people requiring supportive living environments such as long term care (LTC) or assisted living (AL), nearly half are living with some form of dementia (Global Observatory for Ageing and Dementia Care, 2013). In one recent study in a Canadian province, Strain, Maxwell, Wanless, and Gilbart (2011) reported that 58% of AL residents lived with a diagnosis of dementia, as did 71% of residents in LTC. Research has also shown that caring for persons with dementia can be emotionally, physically, and ethically challenging on a daily basis (Bolmsjö, Edberg, & Sandman, 2006) and that turnover in nursing staff in these settings tends to be high (McGilton, Tourangeau, Kavcic, & Wodchis, 2013).

It is within this context that our research team became curious about the possible role of moral distress in the work of nursing providers who care for individuals with dementia. Nathaniel (2004) defined moral distress as the pain or anguish affecting the mind, body, or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgement about the correct action; yet, as a result of real or perceived constraints, cannot do what is thought to be right. In this paper, we report findings from a qualitative study of moral distress in a single health region in a Canadian province. The aim of this paper is to elucidate the sources of moral distress experienced by nursing care providers in the residential care of people living with dementia.

Literature

Research demonstrates that moral distress is a serious issue for care providers in the health professions (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004; Varcoe, Pauly, Storch, Newton, & Makaroff, 2012). For example, various factors that contribute to the moral distress experienced by nurses in hospital settings have been identified such as threats to professional integrity (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2008), system obstacles to care (Varcoe et al., 2012), inability to advocate for patients due to policies or the politics of medical hierarchy (Erlen, 2001; Varcoe et al., 2012), lack of administrative support or respect for nurse's decision-making (Austin, Bergum, & Goldberg, 2003; Pendry, 2007), and a negative ethical climate (Pauly, Varcoe, Storch, & Newton, 2009). Others have noted moral distress in relation to inadequate staffing levels (Corley, Minick, Elswick, & Jacobs, 2005; Schluter, Winch, Holzhauser, & Henderson, 2008), requirements to provide care perceived as futile (Hamric & Blackhall, 2007), and working with colleagues who are inadequately trained or incompetent (Piers et al., 2012). There is growing interest in the effects of moral distress over time on professional work life (Edvardsson, Sandman, Nay, & Karlsson, 2009; Testad, Mikkelsen, Ballard, & Aarsland, 2010), client care

(Todd & Watts, 2005), and staff recruitment/retention (Chenoweth, Yun-Hee, Merlyn, & Brodaty, 2010). It has also been suggested that moral distress is linked with nurses choosing to leave a working environment (Corley et al., 2005; Schluter et al., 2008).

Nurse researchers have explored moral distress, and most of this work has been focused in acute care environments such as intensive care (Lawrence, 2011), emergency room care (Unruh, 2010), and acute care hospitals (Corley et al., 2005; Pauly et al., 2009; Varcoe et al., 2012). However, there has been scant attention to understanding moral distress in residential care facilities and even less attention to how it might be measured in this setting (Pijl-Zieber et al., 2008); this gap persists in the published literature. In a rare study of moral distress that did include nursing home and elderly care environments in the Netherlands, researchers found that respondents working in nursing homes had the highest levels of moral distress (de Veer, Francke, Struijs, & Willems, 2012). These researchers and others concluded that organizational context is critical to understanding moral distress in care providers and that there is, as yet, a very limited understanding of the concept in most care contexts (Pauly et al., 2009; Schluter et al., 2008).

The care context in the current study is residential, continuing care, where many of the residents live with dementia; we found no research that specifically explored moral distress in dementia care. Some research has shown that caring for people living with dementia can be physically and emotionally stressful (Duffy, Oyebode, & Allen, 2009; Pitfield, Shahriyarmolki, & Livingston, 2011). In a qualitative study of ''strain'' experienced by 35 nurses providing care for people with dementia across three countries, Edberg et al. (2008) found that ''a desire to do the best for the residents to alleviate their suffering and enhance their quality of life'' that is thwarted by contextual constraints in terms of opportunities, abilities, and resources was the most consistent and primary source of strain for nurses (p. 238). The authors conceptualized this as ''moral stress,'' (p. 240), a concept they acknowledged as similar to moral distress. We agree, as Edberg's (2008) ''moral stress'' was generated by a tension between what nurses wanted to do for those in their care, and what they actually could do. These researchers identified the need for much more study of this phenomenon in these types of care environments, in order to develop effective interventions to improve the well-being of nursing care providers ''and by extension, those they care for'' (p. 236).

Method

Design

Consistent with the lack of research on moral distress in residential care settings, we employed an exploratory, descriptive design in this study. We sought the perspective of nursing care providers of those living with dementia, in order to gain conceptual clarity and a contextualized understanding of situations in residential care that trigger moral distress.

Setting

The study was situated in one Health Authority of a Western Canadian province, serving the health care needs of approximately 298,000 people. The region has two main population centers with populations of 95,000 and 62,000, situated within a largely rural geography in the southern part of the province. As this study was focused on residential nursing care of

people with dementia, we focused on care facilities providing more complex care: LTC and higher levels of supportive (or assisted) living. LTC is where the most frail and medically complex residents reside, because they require higher levels of professional nursing care that cannot always be scheduled. Facilities at the highest level of supportive living provide care for those with more moderately complex health needs who are living in a home like setting with scheduled support by home care nurses and other unregulated nursing providers. We also included a variant of this level of supportive living that is focused on providing care to those with dementia or other mental illnesses and require a secured environment.

Participants and recruitment

We selected six residential care facilities and three home care sites (central offices for home care registered nurses (RNs) serving one or more care facilities) as sites for recruitment. This selection was based on obtaining variation in size and geographic location (rural vs. urban) of facilities. Entrée to participating organizations was achieved through the Health Authority Senior's Health leadership and proceeded through email contact with managers in each of the participating sites. To recruit participants, the lead researcher conducted presentations in each of the selected sites, leaving behind posters and letters of invitation to participate in the study. Managers were also asked to publicize the study through the further distribution of letters of invitation and by posting materials in their facility. We invited the participation of regulated/licensed nurses (i.e. RNs and licensed practical nurses [LPNs]) and unregulated/unlicensed assistive personnel (i.e. health care aides [HCAs]) providing direct care within facilities, as well as RN case managers providing care management for residents in supportive living environments. Interested nursing care providers were asked to contact the researchers directly and given the confidential means to do so.

   Those who did not participate regularly in the care of residents with dementia or were not at least 18 years of age were excluded. Of the remaining interested participants, purposeful selection was undertaken to ensure we obtained perspectives representing all nursing designations across all facility types; we also were purposeful in selecting across a broad age range and numbers of years in practice (Table 1).

   Ethical approval for the study was obtained through two University Research Ethics Boards in the province. The study was explained thoroughly to those expressing interest, and informed consent was obtained. Participants were also made aware of the implications of provincial legislation—the Protection of Persons in Care Act (Government of Alberta, 2009), i.e. that the researchers were obliged to adhere to all legal requirements, up to and including the reporting of any events that could give the researcher reasonable grounds to believe that there had been abuse involving a resident. Further, the researchers were well prepared to connect participants to supportive resources, in the event that study participation engendered unmanageable feelings of distress.

Data collection and management

Data collection was undertaken by two research assistants who were intensively trained in qualitative interviewing and supported throughout the process by the research team. Data collection proceeded concurrently with data analysis and semi-structured interviews of one

Table 1. Participant characteristics.

Characteristics	N	%
Sex		
Female	15	83.3
Male	3	16.7
Age		
18–30	6	33.3
31–44	4	22.2
45–65	7	38.9
>65	1	5.6
Designation		
LPN	5	27.8
RN	6	33.3
HCA	7	38.9
Location		
Urban	10	55.6
Rural	8	44.4
Experience (yrs)		
1–5	6	33.3
>5–10	5	27.8
>10–15	2	11.1
>15–20	2	11.1
>20	3	16.7

to two hours in length (average 90 minutes); interviews were conducted until no new themes were identified. This was achieved after interviews with 18 nursing staff: seven RNs, four LPNs, and seven HCAs. All interviews were audio recorded and transcribed verbatim by a professional transcriber who was bound by an oath of confidentiality; transcripts were checked by a research team member for accuracy (i.e. consistency with audio files). All data were managed using NVivo version 10 and stored securely on a password protected computer accessible by the research team only.

Analysis

Digital audio files were transcribed verbatim. Participants were assigned individual codes and transcripts were stripped of any personal identifying information. Interview data were then subjected to a thematic analysis approach (Braun & Clarke, 2006), whereby patterns (themes) were identified and constructed through an inductive, iterative process—moving back and forth between data collection and analysis phases (Braun & Clarke, 2006; Morse, Barrett, Mayan, Olson, & Spiers, 2002) . This process commenced with reading/reviewing each transcript and deconstructing the data with open coding of words and phrases. This was followed by the generation of initial codes created to describe "chunks" of text deemed meaningful. Once all transcripts had been coded in this manner, the analysis progressed toward searching for, and identifying, initial patterns (themes) based upon similar units of data across the entire data set. Lower order codes were grouped, compared, and mapped into conceptual categories and as new data came in, they were compared with existing codes

and categories. Categories were fleshed out and refined, altered as new perspectives were revealed, or collapsed into higher order conceptualizations.

Coding was undertaken by three different members of the research team, and two meetings of the whole research team were held in order to discuss emerging themes, and to identify themes that required further clarification or development with subsequent data collection. This iterative approach to data collection and analysis revealed six themes related to sources or triggers of moral distress for nursing care providers in this setting. Each theme was summarized, and member checking was undertaken with interview participants in order to ensure interpretive accuracy.

Findings

"...you just end up doing what you know, morally, is not probably the right thing for [him]...I don't think [he] would have wanted it. But [he] wasn't able to communicate that. So there, you're stuck." The notion of *being stuck*, as described by this participant provided a compelling lens through which to conceptualize the experiences of moral distress for nursing care providers in this study. The nursing voices in the following paragraphs are represented by pseudonyms and reflect the following six themes related to the sources of moral distress as experienced in this setting: conflicting expectations around care, remaining silent, failure to be accountable for care, failures of leadership, the wrong model of care, and a culture of work that privileges tasks over touch.

Conflicting expectations around care

Being stuck in the middle of conflicting expectations around care meant that nursing caregivers not only witnessed but also felt unavoidably complicit in care that they perceived to be inappropriate or inadequate. Virtually all participants shared their distress at feeling bound to provide care that conflicted with their own beliefs and knowledge about what the resident might want or need, especially as the care providers closest to the resident at this point in the resident's life. Such conflicts most often arose in interactions with families, as RN Meg explained:

> I sometimes think that a lot of the moral distress comes from family dynamics. Like a lot of the time that's what I find interferes a lot with different care and what's to be done. Because you as the nurse, you are educated, you know what the resident needs. You've been educated to know what dementia residents specifically, need. But then you are trying to explain this to family members and they don't understand it, so they are still going to do what they are doing...and I feel like, the family is not here all the time we're here. We are their eyes, their ears - we see more than probably sometimes the family even does.

The expectations of families to provide what nursing care providers believed was futile or inappropriate care for the resident with dementia was another source of moral distress. For example, RN Erin explained:

> I've had dementia clients where [the family] wants full resuscitation and they don't want to change the level of care even to maintenance level or to comfort care. And so because of that, it involves a lot more hospital intervention and different procedures and things which may be way more aggressive than the person [would want]...[or is]...appropriate.

Conflicting expectations around care can also lead to family members interfering in what nursing care providers see as necessary or even essential elements of care. For example, LPN Barb described:

> We have some couples, and the husband is our client (the wife is not). And the wife interferes with the day to day care of the client. And our staff are really, really great caregivers and they are doing their best . . . you go home some nights saying, "I just couldn't do the best I wanted for this gentleman", because the wife interferes with having you do [his personal care].

RN Steph shared her feelings of powerlessness as she witnessed what she saw as the consequences of having to abide by family expectations that didn't meet a resident's needs:

> So the issue became, how do we control his aggression and anger? And the family weren't on board with any medication whatsoever . . . [the family decision-maker] discontinued all his medications and fought against everything. And then, eventually, the client just stopped eating and stopped drinking and died. And it was just a horrible, nasty situation . . . his guardian was the one who made the decision and I couldn't do anything . . . my hands were tied.

Most nursing care providers observed that conflicting expectations with families often resulted in feelings of distrust and anger on the part of families; RN Cathy noted "we are all getting it, we field angry families daily." RN Erin further explained:

> . . . it's like there is a distrust that happens when somebody is trying to protect somebody that is demented. Because they realize [the resident] can't make their own decisions, so they've taken on that responsibility . . . So they feel it's their responsibility to protect [the resident]. But in doing so the caregivers become the enemy.

Although family expectations were mentioned most frequently, other sources of conflicting expectations included physicians that only visited infrequently, leaving documented expectations in their orders that did not reflect the reality of the resident's situation, or address current concerns. RN Jen noted:

> . . . and I think sometimes there's a lack of understanding by physicians too . . . they have a bit of tunnel vision too. Because they see, you know, "this is, this is my resident . . . this is what's wrong with them, this is what I expect to happen", right?

LPN Maria made it clear that by the time physician orders were received, they were often based on an outdated understanding of a resident's needs:

> . . . at the beginning [the resident] was just a little angry, [but] then she become verbally aggressive . . . and now she's physically [aggressive] . . . but I had a problem with the physician . . . I asked on Thursday if he can get something for her behaviour scheduled . . . maybe once a day or twice a day, but he [gave me] only Seroquel [only as needed] . . . Seroquel doesn't do much given [only as needed], as it won't have much effect and consistency to help with her behaviour . . . they are not here and they don't see the real situation and they think, "oh, I know what is good" and they fax me an order and [they think] that's gonna (snaps fingers) solve all the problems but, sometimes, it is not that easy . . .

Moral distress was also generated when providers saw a need for timely care and witnessed the reality of delayed medical care as an expected and unchallenged feature of LTC. LPN Tim observed: ". . . in long term care, it's like oh, we can put that off. We can put [that] off until next Friday . . . you know what I mean? It's like a rarity that doctors regularly

come . . . to long term care to see their patients.'' Nursing care providers were with residents as their needs changed, and witnessed the consequences of delays in needed care by physicians. Tim further commented on how this made him feel:

> And you don't know when that doctor is going to come to write an order, so that you can stop [the pain]. Like you just feel like a total failure . . . And I was like you've got to be kidding me? Like this is ridiculous. Like you were called on Tuesday. You are going to come on Friday?

Remaining silent

The notion of being stuck in a course of action that felt wrong because one felt unable to speak up was noted by several participants. Sometimes remaining silent was due to the reluctance to question someone who was perceived to have a higher status and more knowledge as RN Meg (who started out as an HCA) explained:

> I remember one time a lady had broken her hip . . . I was already in training so I kind of already had the assessment down. And the one nurse - she just told me to lift her back up and put her in her chair. But I knew it was wrong the whole time. And I felt bad for the lady because she was probably in pain . . . if you did the right kind of assessment you would know that she would have been in pain. And maybe gave her interventions and maybe got the ambulance here right away - which she didn't do . . .. I was a HCA at the time and I had that mentality you do not step on your, on your base above . . . and I don't know, maybe that's a bad mentality to have . . . but I just, I don't step on what the nurse's decision is because she is supposed to be in charge. She's supposed to know, so . . ..

Several other participants, like HCA Sue described staying silent in order to avoid the consequences of speaking up:

> I just personally have a hard time - I'm struggling right now with the fact that I really want to make huge reports about [a situation]. But then, sadly, in the back of your head you are like . . . 'you are going to pay for it in the long run with your job and then your job is going to be harder' and then . . . so I'm struggling with that one right now . . .

RN Meg further noted:

> Yeah, you're worried . . . like ''am I going to get into trouble? I brought this forward, do they think it's me?'' Or, ''am I going to have a bunch of crap happen to me now?'' Because these are people I work with. ''Is that going to affect my work?'' You know what I mean? There's a lot of things to think about . . . you know, I have to work with these people every day. And if I am . . . bitching at them all the time to do their jobs, they are going to hate my guts. And it's really hard to work with people that hate you.

Nursing care providers knew that the right thing to do was to break their silence, but felt constrained from doing so; some—like HCA Sue—even felt bullied into silence:

> I do go home at night and - it kills me because, I'm like, you know - I've taught my kids that bullying is not allowed. And if you stand by . . . they even said to me, ''Mom you are doing the exact same thing. You're just standing by and you are not doing anything''. So I'm really struggling with - every day I keep going, ''I'm going to the manager.'' But I haven't gotten there quite yet . . .

Failure to be accountable

All types of nursing care providers reported moral distress when they witnessed others on the care team failing to take accountability for providing quality care. As LPN Hazel explained,

> [Some co-workers will say], "oh I am a float, I'm never on that floor". I'm like—"but you know what? You were on that floor, that's your responsibility too." Just because you are the float and you get moved around - that's [still] your responsibility while you are there. And a lot of people they don't get that. They think, "oh, I'm only here for one or two days . . . I won't follow-up on anything." . . . they . . . just leave it for the next shift.

A failure to be accountable was seen to have serious implications—up to and including situations where care truly suffered, as described by HCA Liz:

> . . . there was an elderly gentleman who couldn't move or get out of bed . . . he had Alzheimer's quite . . . severe. And his care was neglected totally. He had pressure sores that were infected and disgusting on his bottom. And he wasn't being cleaned. Nothing. And I went in there and saw what exactly . . . the kind of condition he was in and I was not happy. And so we cleaned him up, we changed his dressings and I mean we just - the full deal. Like we couldn't believe it . . .

Situations such as the one described above left nursing care providers demanding consequences for colleagues who were seen as having failed these vulnerable residents. LPN Hazel put it this way:

> I'm saying that if you don't do your job properly you can't be an employee here or maybe you should be suspended or get some more education . . . there has to be consequences for not doing your job. You know, you are not just a body on the floor giving out medications . . .

Hazel further elaborated that a lack of training sometimes set the stage for accountability failure, particularly for providers who did not understand the consequences of their care decisions:

> I think if they did have the education [about] this causes pressure ulcers . . . if they are incontinent it's going to cause open sores in their groin. If you don't wash them properly, they are going to get a yeast infection or some bacterial infection, a UTI. You know, their health is going to go down. All these things interlink . . .

Although a lack of knowledge was not suggested as an excuse for poor care, it was noted that it was difficult to hold people accountable for things they didn't know they were supposed to do. As RN William explained:

> . . . say for a client that has verbal aggression, we could go to a best practice team get some suggestions how to redirect the client, how to minimize aggression, how to educate staff to deal with the behaviour as well, because you know, the HCA staff gets really no education in that. So that's often where you will see instances where people get, not neglected or anything but like a lot of the HCA's don't have the education to really understand how to deal with things like that properly.

Leadership failures

Leadership failures were most visible to participants when formal leaders failed to follow up on identified failures of accountability for care. Several participants shared their moral

distress at repeatedly witnessing and reporting situations of failed accountability, but no action being taken. LPN Hazel observed:

> . . . I just go to my boss and say, "you know what? Can you talk to this person, maybe tell them they are not doing this properly?" Or, you know, "just have a discussion with them." I don't know if anything happens because she doesn't follow-up with me or anything like that. Or . . . sometimes I will ask her, "did you talk to that person?" And she'll say, "yes," or "no." Because sometimes she doesn't follow- up with it . . . and she'll just say, "oh, I forgot". But I think a lot of the problems that we have . . . is actually administration - dealing with the problems.

Managers were also seen by nursing staff as sometimes being stuck in a system that set that set them up for leadership failure—constrained from taking the right action because of institutional expectations, regardless of circumstances: As described by HCA Louise:

> . . . we're still stuck in a room because we only have so many staff members then we know that the family is going to be in, right? We know that the family hightails it straight to the manager's office and is complaining about our care . . . which is frustrating because we're doing the best that we can and that manager may not see everything that we are doing and so he's siding with the family, because obviously he has to, right?

LPN Barb observed that even capable managers often found themselves similarly constrained in their positions: "we never feel angry at our, at our manager I don't think, ever, you know, I mean it's out of her hands. She really does a great job but . . . you know . . ." Others noted that those in positions of leadership and decision-making did not have any understanding of the reality of LTC environments. HCA Fiona observed:

> Too many minds, too many managers. The people who give out orders have never been in a place like this before . . . they've never, they don't know what a long term care facility is all about. They, they have no idea. Come in and work with me. Come with me [Health Minister], let's go in here and work for an hour. I'll show you what life is really like. You know, that's what frustrates me.

In other cases, nursing care providers related their distress caused by failures of leadership at the level of direct care. HCA Tina explained:

> Well we have this one lady . . . if you just touched her, just lightly on the arm, she would be in so much pain. Like, "that hurts, that hurts!" So, I reported it and reported it and reported it and reported it. And this poor lady only gets Tylenol - which I don't think is enough if she's in that much pain . . . you keep reporting it and I don't think anything has been done about the pain . . . they haven't increased it . . . we've reported it to our RN . . . its up to the RN to phone the doctor or . . . get the physician to come in or talk to the family or whatever. And still nothing. So it's hard. But you just keep bugging them and keep saying the same thing and keep telling them, telling them, telling them . . .

Wrong model of care

This theme captured observations where participants noted that structural elements of the care context were mismatched to the needs of the residents in their care. These elements included inflexible models and imposed levels of care, and inadequate resources to meet the needs of those in care. Participants shared their feelings of moral distress as they tried to

meet the needs of their residents, within a model of care that just did not seem to fit—a model that left them feeling stuck on the wrong path. Residents with dementia were seen to be in a place that didn't meet their needs and that facilities themselves were seen to be "stuck" with models of care that didn't work for this population. RN Cathy who provided care management to residents in supportive living facilities noted:

> And I have empathy for how hard it is for [those running supportive living organizations]. If you want to look at the staffing, the very way the model is set out . . . it's not supposed to be a medical model. It's supposed to be a social model . . .. And the fact of the matter is, we are taking people and placing them in these facilities that have three or four chronic diseases, and they are medical, they are there because they were too medical to keep anywhere else . . . It's ridiculous to say that we can manage these medical things and still make it homey.

Similarly, RN Steph indicated that frustration was common among colleagues, especially when being placed in a position of having to "sell" a model of care they found to be inadequate to meet needs:

> . . . we can put a person in there and we tell our clients the care level will be as good as maybe the lodge . . . the care level is not . . . they are . . . just not getting the care and I feel bad, because I have already said to the family that the care is going to be the same. Because that is supposedly what is going to happen. It doesn't happen.

LPN Hazel described residents with complex needs not getting the care they needed, because the model was wrong for many residents:

> . . . it makes me feel upset . . . it makes me feel angry too, that people are getting away with treating people this way. And I think it's wrong. These people pay taxes all their lives. They need to be provided proper care . . . right now we are [categorized as] supportive living and it's ridiculous. It's long term care but you pay for your own stuff now. That's what it is.

Frustration about the model of care was not limited to supportive living, however. Nursing providers in LTC settings also perceived that the model of care created situations that caused moral distress. HCA Susan described her perceptions this way:

> . . . it's just degrading and it makes me really feel like we're disrespecting these people. . . . you're taking away everything from them . . . and then here we come in, proclaiming to be caregivers and all we really do is take away their basic rights of being able to do whatever they can for themselves. Yeah, it's sad . . . and . . . frustrating.

It was also noted that the particular needs of the resident with dementia often introduced challenges in terms of getting people to the right level of care. RN Cathy noted that "We don't have facilities that are set up for our people with aggression" and RN William described the distressing trade-offs made in order to meet needs; for example, getting someone with difficult behaviors to a secure environment because it was the easiest place to manage the behavior, although such a placement meant that "they are going to progress faster in their dementia because they are not receiving that social aspect." Sometimes, it was believed that actions were taken to make the resident fit the criteria for the setting, rather than the other way round. As RN Cathy explained:

> . . . behaviours would escalate and they would add a little more medication and eventually were sort of maxed out in what you can do with the medications. And even that in itself is a distressing

thing to me, because it's impossible to give them the medications so that you can keep them where they are - so that they don't hurt somebody else - without causing them some side effects . . .

Closely related to concerns about models of care was how the right care was constrained by shortcomings in terms of structural supports like staffing, resources, and equipment. As RN Jen described:

> . . . staffing is always an issue. And on just about any given day, you're short of front line caregivers, the HCAs that do the front line work. And so it's hard as the RN or a manager to intervene and ask them to do things that they can't do because of those, you know, because of a lack of time or lack of staff . . .
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> . . . and . . . like I said to the manager the other day . . . you need to start making some noise now about equipment before we get [the resident] here. Because otherwise, how do we expect staff to care for somebody like that? You know? And then you put staff in a position where they are at risk; they are demoralized, because they can't do the proper care . . . they are struggling physically, emotionally . . .

RN Erin observed that providing care to a growing population of seniors with dementia was very challenging in an era of tight budgets: "We work mostly with seniors . . . it just keeps growing and growing and growing. But, to actually get more staffing is a very difficult process . . . there's always cutbacks happening, right?" HCA Judy described the distressing position a nursing care provider is placed in when there are not enough resources allocated to meet needs:

> . . . you're often placed between residents. You have to pick which one needs your assistance more at that time . . . it often happens that one resident needs to go to the bathroom and another one needs assistance doing something else . . . you have to stop and make that choice . . . that's kind of unfair to the residents.

A culture of tasks over touch

As a result of the constraints described above, lacking time to provide good care that respected the humanity of residents was raised by several many participants. LPN Shelly observed:

> . . . there's no time . . . I [have] twelve people and somebody doesn't show up. And everybody has to be at the table by nine o'clock for breakfast. And so you are doing things as fast as you can, and not doing a good job and so people do miss their bath that day and all I am going to really do is dress them and [personal care] and those basic things.

Indeed, most participants across all designations communicated a need to race against the clock in order to get everything done in contexts where staffing and resources were challenged. Participants discussed that such persistent constraint fed a tendency to default to time-efficient approaches versus taking the time to honor another's humanity. For instance, HCA Susan elaborated upon a situation involving meal times:

> . . . a lot of our residents - they do take a ton of time to eat on their own . . . and I figure . . . as long as they are still doing it themselves, they should be allowed to. Where because of our time constraints you know, lunch gets served at twelve o'clock but [many residents] . . . get laid

down in the afternoon . . . so you have to have these people toileted and in bed before one thirty . . . and I've noticed that at our place the trend has been . . . to give them drinkable meals . . . which to me is, is revolting . . . so I am always arguing . . . why are we doing this? Because you don't have the patience to sit and wait for them . . . because you've got your schedule . . .

HCA Liz explained that this kind of "hurry up" care had other negative consequences, including for the technical quality of care:

"I'm sorry I forgot the pill cup, I was in a hurry", and you know, a little bit of an argument between me and this family member, and I didn't think anything about it. I was kind of like, upset because I was trying to do the best I could, and you're always rushing– I find I have to find a way of to slow yourself down when you are in that setting because you just get in a hurry, and sometimes that affects your quality of care and I made a mistake and I made an error, whatever you want to call it. I messed up.

In this time and resource constrained context, a number of participants discussed the perceived pressure to take the "easier" versus "right" path with respect to administering medication. RN William struggled with this: ". . . the medications are such an easy fallback. And they are so devastating to the integrity of the person who is getting them." Similarly, LPN Tim indicated that often, following administering medication, ". . . [the resident] falls asleep and then everyone is like, "oh, that's good." And I'm like, "oh, really, is it?" RN Meg noted "to me you shouldn't be giving [a resident] medications to just shut him up . . . I don't believe in that." Participants also spoke of the easier versus right alternative as it pertained to deceiving residents in order to avoid adding time and complexity to care. For instance, HCA Robert experienced moral distress when he knowingly deceived widowed residents in his care:

. . . maybe their spouse has passed away and they keep asking for them . . . in a lot of cases we know we should tell them the truth because, you know, that's the right thing to do. But a lot of times we generally have to tell them that they're at work or they're out doing something just to kind of calm them down because we don't want to get them upset . . . I do think that lying . . . is probably the best way [to ensure] we don't get them upset every time that they're asking . . . But it is, you know, difficult to have to lie to them too . . .

Deception of residents was also employed to expedite other tasks as well. RN Jen observed:

. . . you are put in a position where I've got to get this medication into this person, so let's crush it and hide it in the ice cream, you know? And, I mean, I guess some of the time . . . it seems okay. But lots of times it doesn't seem okay . . . to me that just doesn't feel right . . . If I walk up to the client and I - I've always tried to tell my staff, instead of . . . trying to pop the pills in their mouth, put the pill in your hand so they can see it. Even a resident with dementia understands what that is. They'll pick it up and put it in their mouth. But if you are trying to shove it down their throat, I mean, you are going to get resistance.

Our interpretation of these findings highlights what may be considered the origin of moral distress for most nursing care providers in this study: a place of deep and genuine caring for people with whom these providers have developed relationships over a long period of time—often years. They experienced distress when working in a setting that created the conditions for a prevalent culture of tasks over touch—a culture that left room for some

care providers to display uncaring attitudes as a matter of course. For example, LPN Hazel noted:

> . . . there's a lot of people that do not care. And I know that they don't. They are very rude to the residents. They don't talk to them. Like I mean, whip them out of bed, put your clothes on, as fast as you can, down to the dining room, as soon as you are done eating you are right back in bed. So you don't have to bother me.

In fact, when witnessing the ''uncaring'' place that some colleagues had come to over time, LPN Hazel related her distress in terms of what it might mean if she was temporarily absent from the institutional environment:

> I always think no one is going to do it the way that I do it. And I just worry about them. Because sometimes I just get really stressed out thinking, ''I wonder if everybody is okay,'' you know? It's upsetting.

Discussion

Our aim was to elucidate the sources of moral distress experienced by nursing care providers in the residential care of people living with dementia. Our analysis revealed six main themes, interpreted through a lens which conceptualized participants as feeling ''stuck.'' Many participants felt bound to provide care that conflicted with their own beliefs and knowledge regarding what was most appropriate (*Conflicting expectations around care*). Participants also indicated they often perceived themselves to be stuck in a course of action that felt wrong due to feeling unable to speak up and voice concerns (*Remaining silent*). Moral distress was also experienced by all types of nursing care providers when witnessing other care team members failing to take accountability for the provision of quality care (*Failure to be Accountable for Care*) and when formal leaders were perceived to have failed to address such concerns (*Failures of leadership*). From a structural perspective, many participants perceived elements of the care context to be mismatched with the needs of residents (e.g. inflexible models and imposed levels of care as well as inadequate resourcing) (*Wrong model of care*). Our interpretation of the findings also suggests the emergence of a ''care culture'' that is incongruent with core nursing values of caring and compassion (A c*ulture of tasks over touch*).

These findings are important in helping illuminate the sources of moral distress in residential care and in demonstrating that moral distress is an ongoing feature of the experience of nurses providing care to people with dementia living in these settings. The experience of ''being stuck,'' unable to provide care according to one's firmly held belief about what was right, was a familiar one for these participants. In many ways, the results of this study are congruent with the findings of other studies, and we will discuss those similarities here. We will then explore three distinctive features of this care context that appear to underpin the sources of moral distress experienced in this setting: the nature of the relationships between providers and residents, the implications of dementia, and the perceived lowly status of the continuing care sector in Canada.

We found that moral distress was triggered when nursing care providers witnessed what was perceived as medically aggressive and futile approaches to care, as well as the painful consequences of such care for residents; this is consistent with the findings of others (Ferrell, 2006; Pendry, 2007; Piers et al., 2012; Schluter et al., 2008). The findings of moral distress

being triggered by witnessing colleagues eschewing their responsibilities to provide competent, high quality care were also consistent with other studies (Corley et al., 2005; Piers et al., 2012), as were situations of poor staffing leading to rushed, impersonal care (Austin et al., 2003; Burston & Tuckett, 2013; Edberg et al., 2008; Varcoe et al., 2012), and the objectification of patients in institutional models of care (Corley et al., 2005; Nathaniel, 2004). Further, the participants in this study identified failures in leadership support and lack of follow-up on care issues as sources of moral distress, as well as the constraining effects of healthcare power hierarchies—observations that are also consistent with research in other settings (Austin et al., 2008; Pendry, 2007; Unruh, 2010; Varcoe et al., 2012). Finally, being caught between family expectations and what the participants believed to be appropriate care as a source of moral distress has been identified by others (Corley et al., 2005; Gutierrez, 2005; Zuzelo, 2007). We suggest that what our findings add to the existing literature related to sources of moral distress in nursing care may be related to three somewhat distinctive features of this care context: long-standing and close relationships with residents and families, the implications of dementia for care and relationships, and the overall low priority status accorded this sector of care within the health care system.

Relationships with residents and families

In residential care settings, relationships between care providers and residents typically extend over many months and years. Indeed, it has been noted that the closeness of these long term relationships and the emotional connection experienced between care providers and residents significantly contribute to a nursing provider's desire to stay working in the setting (McGilton & Boscart, 2007; Prentice & Black, 2007). Many nursing care providers in this study told us that they believed they knew the residents' needs best, as they were consistently present with residents over the long term, bearing witness to how their needs changed over time as dementia progressed. It is perhaps not surprising that these providers experienced moral distress when faced with care imperatives that did not seem right for a resident, especially when those imperatives came from physicians that rarely appeared in the setting or even from families that were not involved in the day-to-day care of a resident. However, the value of a care provider's judgement with respect to the individual's needs has been problematized within the literature. In fact, Johnstone and Hutchinson (2015) questioned the validity of the concept of moral distress altogether and challenged the implied assumption that an individual nurse's judgment of what is right trumps the judgments of others. Moral distress may indeed be a flawed concept as currently understood, but there was no doubt that the nurses in this study felt morally distressed when asked to provide care that they believed ran counter to what was best for the resident—it was also clear that long experience with a resident contributed to the nursing provider's sense of justification in holding that belief. The nature of the relationships with these vulnerable residents contributed to an acute sense of protective accountability in many of our participants and engendered deep distress in many when they perceived others to be shirking accountability in care or proceeding in ways that didn't best meet a resident's needs.

The long term nature of the web of relationships around a resident in care truly compounded the identified triggers for moral distress: conflicts around expectations became chronic in many instances and even intensified as a resident's needs evolved and increased. As one participant put it, the care staff ''became the enemy'' as families became increasingly protective of a failing loved one, while the nursing staff providing daily care

grew in their conviction that they were also protecting the resident by providing care that met resident's needs best.

The implications of dementia

The implications of providing care over sustained periods of time for residents living with a complex illness like dementia influenced the experience of moral distress in a number of ways. Since residents with dementia experience deteriorating abilities to clearly communicate needs, and an increased likelihood of unpredictable and sometimes aggressive behaviors, the potential for reciprocity in relationships with residents that nurses in this care sector identify as deeply gratifying is decreased (McGilton & Boscart, 2007; McGilton et al., 2013).These features of dementia also create a demand for higher levels of knowledge about assessment and appropriate care, yet caregivers in this study were clear that the knowledge gap in this setting was growing, rather than shrinking. The bulk of the care was being provided by unregulated nursing providers who acknowledged that they were not receiving the training needed to know the right way to proceed in many situations. Similarly, regulated nurses felt that resource pressures had constrained their ability to mentor less knowledgeable providers in dementia care strategies, which added to their distress when they witnessed colleagues providing less than adequate care. Further, many expressed their awareness of how rushing care for residents with dementia increased the likelihood of resistance or even aggressive behavior, and a conflicting, simultaneous awareness of a need to "race against the clock" in order to get all the work done for the day. Finally, the desire to adequately address the complex and evolving needs of residents with dementia ran squarely into what was perceived as a rigid, unresponsive, and under-resourced model of care—one that didn't fit most residents with dementia very well.

The "forgotten" sector

Finally, there was a strong sense from participants that this sector of care was the "poor cousin" of the health care system—the sector where it seemed more acceptable to cut corners with resources, reduce skill mix, and pay less attention to issues around care. Participants spoke about being at the "very bottom of a very long food chain," where even their own leaders were powerless to effect much positive change. How paradoxical that providers in this setting felt the press of time each day in their efforts to meet multiple competing needs, and yet witnessed situations where even needs they perceived as more urgent were not addressed in a timely way by the medical system—as if there was "no hurry" given the nature and level of care.

   Participants in this study felt the imperative to advocate on behalf of their vulnerable clients and many did so repeatedly—despite the factors constraining that advocacy. Recalling Nathaniel's (2004) definition of moral distress discussed earlier, these caregivers did feel anguish in response to situations where they were aware of a moral problem, acknowledged moral responsibility, and made a moral judgment about the correct action. They also perceived constraints to moral action, but in many cases still took action, but experienced no moral outcome and consequently felt morally distressed. Varcoe and her colleagues also noted this finding and discussed its possible connection to the relative power positions of nurses within health care hierarchies (Varcoe et al., 2012). In this study, the entire sector of care was perceived as being in a disadvantaged power position in health care.

Implications

We believe our interpretations offer important insight into the sources of moral distress among nursing care providers in continuing care settings. However, we acknowledge there are several important limitations of our study. For instance, the transferability of these findings is limited. Although we sought participant variation with respect to the care setting, work experience, participant age, and sex, the sample was selected in a purposive manner from one geographic region in Canada. The extent to which our findings reflect the experiences of other nursing care providers in other settings is unclear. It is also possible that participants chose not to disclose some of the most distressing elements of their experience, given the declaration by the researchers that they would be abiding strictly by the provisions of the Protection of Persons in Care Act.

Despite these limitations, our findings suggest that moral distress plays a significant role in the experience of nursing care providers who care for people with dementia in LTC and AL settings. Although it would be inappropriate to suggest the frequency or intensity of the experience based on this qualitative study, it is reasonable to assume that the experience is not uncommon based on how the phenomenon resonated with participants, and how easily they were able to share examples of its presence in their experience. It follows that moral distress may be adding to staff recruitment and retention challenges in a sector that faces high nursing turnover. This is especially concerning at a time when a large and growing aged population are living longer and potentially requiring residential care—particularly as the incidence of dementia rises over the coming decades. This research also makes it clear that further research efforts focused on assessing the frequency and intensity of moral distress in residential care settings are important, along with efforts to design and test interventions aimed at addressing moral distress.

Conclusion

These findings contribute to greater conceptual clarity around the possible sources of moral distress in this setting. Although these nursing care providers did not always refrain from acting or knowingly take the "wrong" action as the conceptual definition might suggest—they did describe many situations where they felt "stuck," constrained from taking what they believed was the correct action. The integrity of the core of the concept: anguish experienced when a person feels constrained from doing the right thing—is supported by the observation that the sources of moral distress in this setting were similar to those identified in other settings. It is noted, however, that contextual variables residing in the nature of the relationships formed, the features of dementia, and the provision of care in a sector that seems forgotten contributed to the unique experience of this phenomenon in this setting.

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