Caring in the wake of the rising tide: Moral distress in residential nursing care of people living with dementia

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Abstract
Objective: Moral distress is increasingly being recognized as a concern for health care professionals. The purpose of this study was to explore the nature and prevalence of moral distress among nursing staff who care for people living with dementia.
Methods: This study was focused on nursing staff caring for people with dementia in long-term care and assisted living sites. The Moral Distress in Dementia Care Survey instrument was distributed to 23 sites and nursing staff rated the frequency and severity of situations that were identified as potentially causing moral distress.

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Results: Moral distress is prevalent in the nursing staff who provide dementia care. Nursing staff reported experiencing moral distress at least daily or weekly. Both frequency and severity of moral distress increased with proximity to (amount of time spent at) the bedside. Moral distress had negative psychological and physiological effects on nursing staff, and affected intention to quit.

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 most people living with dementia live in the community, nearly half of persons with dementia live in residential facilities offering some form of nursing care, such as long-term care (LTC) or assisted living (AL) facilities (World Health Organization, 2012). Not surprisingly, the majority of the residents in LTC or AL facilities have dementia. For example, in one recent Canadian study, 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. Although there is growing concern about the "rising tide of dementia" in Canada (Alzheimer Society of Canada, 2010), and indeed around the world (Global Observatory for Ageing and Dementia Care, 2013), little is known about the implications for nursing caregivers in care settings that provide the highest levels of care for those living with dementia. Researchers have found that caring for persons with dementia can be emotionally, physically, and ethically challenging (Bolmsjö, Edberg, & Sandman, 2006) and that nursing staff turnover in these settings is high (McGilton, Tourangeau, Kavcic, & Wodchis, 2013). However, the nature of these stressors has not been explored, particularly as they impact different types of nursing staff.

It is within this context that our research team sought to explore the nature and prevalence of moral distress among nursing staff caring for individuals with dementia. Nathaniel (2003) described 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 judgment about the correct action; yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing (p. 22).

In this paper, we report on the quantitative findings from a two year, mixed methods study of moral distress among three types of nursing staff who care for people living with dementia in LTC and AL facilities. We use the term "nursing staff" to encompass all of the various designations of nursing caregivers commonly working in these settings: registered nurses (RNs), licensed practical nurses (LPNs), and health care aides (HCAs, personal support worker, or nursing assistants).

Literature review

Research demonstrates that moral distress is a growing issue for health care professionals, including nurses (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004; Pauly, Varcoe, Storch, & Newton, 2009). Causes of moral distress experienced by nurses in hospital settings have included loss of professional integrity (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2008); system obstacles to care (Mauleon, Palo-Bengtsson, & Ekman, 2005); inability to advocate for patients due to institutional policies (Edwards, McClement, & Read, 2013; Erlen, 2001; Tiedje, 2000); lack of administrative support for nurses' decision-making (Austin, Bergum, & Goldberg, 2003; Gutierrez, 2005; Pendry, 2007); a negative ethical climate (Pauly et al., 2009); perceptions of inadequacy in staffing (Allen, 2003; Corley, Minick, Elswick, & Jacobs, 2005; Schluter, Winch, Holzhauser, & Henderson, 2008); perceptions of futility in the provision of required care (Edwards et al., 2013; Pendry, 2007); and, working with incompetent or inadequately prepared colleagues (Corley et al., 2005).

Moral distress has been shown to negatively impact professional work life (Edvardsson, Sandman, Nay, & Karlsson, 2009; Testad, Mikkelsen, Ballard, & Aarsland, 2010), patient care (Todd & Watts, 2005), and staff recruitment/retention (Chenoweth, Yun-Hee, Merlyn, & Brodaty, 2010; Corley et al., 2005; Pendry, 2007; Vernooij-Dasssen et al., 2009). Moral distress can also cause nurses to experience a range of individual psychological consequences such as anguish, anxiety, guilt, sorrow, anger, frustration, mood fluctuations and irritability, loss of self-worth, depression, nightmares, helplessness, and powerlessness (Gutierrez, 2005; McCarthy & Deady, 2008; Mauleon et al., 2005; Tiedje, 2000; Zuzelo, 2007). Austin et al. (2003) noted that many physical symptoms accompany moral distress, such as headaches, stomach problems, and other physical reactions. Cheung and Chow (2006) have also noted that when nursing care providers experience moral strain, it can have negative spill-over effects on the well-being of older residents.

Most of the research regarding moral distress in health care has been focused on acute care environments (Corley et al., 2005; Cummings, 2010; Pauly et al., 2009; Unruh, 2010). Researchers agree that organizational context is critical to assessing moral distress in health professionals, but conclude that moral distress is poorly understood in most care contexts (Pauly et al., 2009; Schluter et al., 2008). In particular, continuing care environments are one of the least understood contexts of moral distress (Pijl-Zieber et al., 2008).

Instruments to measure moral distress have been developed, although their sphere of relevance mirrors the emphasis in the literature on acute care settings. Seminal work was done based on Jameton's (1984) classic definition of moral distress by Corley, Elswick, Gorman, and Clor (2001), who developed the Moral Distress Scale to measure the concept in hospital nursing practice. This work has been adapted by numerous researchers and used to further study the ethical climate of general hospital settings (Varcoe, Pauly, Storch, Newton, & Makaroff, 2012), intensive care environments (Elpern, Covert, & Kleinpell, 2005; Hamric & Blackhall, 2007; Hamric, Borchers, & Epstein, 2012), nurse-anesthetist practices (Radzvin, 2011), community hospitals, mental health and chronic care institutions (Eizenberg, Desivilya, & Hirschfeld, 2009), and pediatric oncology settings (Lazzarin, Biondi, & Di Mauro, 2012). Recognizing the importance of context to the study of moral distress and the lack of attention to the study of the construct in nursing care within the aged care sector, other researchers have engaged in instrument development more specific to this context. In the Netherlands, de Veer, Francke, Struijs, and Willems (2013)

developed an instrument designed to discover the job characteristics and factors contributing to nurses' moral distress across environments including acute care, home care, and nursing homes (although at the time of this writing, we were unable to obtain the instrument in English). Piers et al. (2012) also constructed a survey to explore the sources of moral distress in nurses caring for fragile older adults at the end of life, incorporating elements of the Corley et al. (2001) instrument, as well as scales related to burnout and the environment of care.

We believe that in light of the increasing prevalence of dementia in LTC and AL facilities, and the likelihood that nurses working in these facilities are also experiencing moral distress, that there is a clear and pressing need for research on moral distress among nurses working in dementia care. In particular, research is needed to measure the presence, prevalence, and intensity of moral distress, the situations that may trigger feelings of moral distress, and the consequences in nurses caring for persons with dementia. This knowledge is needed if moral distress is to be mitigated and prevented in dementia care settings.

Therefore, the focus in this paper is to present the results of a Canadian study exploring the nature and prevalence of moral distress among nearly 400 nursing staff caring for older persons in LTC and AL facilities.

Methods

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 AL sites. LTC is where the most frail and medically complex residents reside; these residents require higher levels of professional nursing care that cannot always be scheduled (Strain et al., 2011). AL sites are classified to 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 unregulated nursing providers (Strain et al., 2011). We also included AL sites that provided care to individuals with dementia or other mental illnesses who required a secured environment. The study encompassed 30 different care facilities employing approximately 3000 nursing staff across both rural and urban settings. Facilities were wholly owned and operated by the health authority or were private/corporate facilities contracted by the health authority to provide services.

Nursing staff who were sampled included RNs, LPNs, and HCAs. In Canada, unregulated, non-professional workers such as HCAs (also called nurses' aides, nursing attendants, or personal support workers) provide 75% to 80% of direct care to LTC residents (Estabrooks, Squires, Carleton, Cummings, & Norton, 2015). HCAs spend most of their workday attending to personal care needs of residents (Mallidou, Cummings, Schalm, & Estabrooks, 2013) and work under the supervision of a regulated nurse (Cranley et al., 2012). Regulated nurses, including RNs and LPNs, are typically further from the bedside, with HCAs providing the vast majority of direct personal care (Bedin, Droz-Mendelzweig, & Chappuis, 2013; Heath, 2012; McGilton, Bowers, McKenzie-Green, Boscart, & Brown, 2009).

Participants and recruitment

To recruit participants, the lead researcher and research assistants conducted presentations in each of the selected sites, leaving behind posters, letters of invitation to participate in the study, adequate numbers of paper surveys to accommodate responses from all nursing staff at the site, as well as confidential, locked drop-boxes for collection of the completed surveys. We invited the participation of regulated/licensed nurses (i.e. RNs and LPNs) and unregulated/unlicensed assistive personnel (i.e. HCAs) providing direct care within facilities, as well as RN case managers providing care management for residents in AL environments. Overall, approximately 2200 nursing staff were invited to participate. We further asked managers to publicize the study through the further distribution of letters of invitation and by posting materials in their facility.

Design

Our development of the survey instrument was informed by thematic data gleaned from qualitative interviews with nursing staff in the first phase of this mixed methods study; these qualitative findings are reported elsewhere (Spenceley et al., 2015; Spenceley, Witcher, Hagen, Hall, & Kardolus-Wilson, 2015). We first piloted the resultant multi-scale survey instrument, the Moral Distress in Dementia Care Survey (MDDCS), in seven sites with participants from all nursing role designations, obtaining a 62% response rate ($n = 68$). Data from the pilot helped us assess the validity and reliability of the MDDCS, and informed minor changes to the survey prior to its final distribution to the remaining 23 sites.

We designed the final MDDCS instrument to collect basic demographic information, as well as data related to the frequency of situations that triggered moral distress, the magnitude of distress caused, the consequences to providers in terms of physical health and job satisfaction, and the perceived effectiveness of particular strategies to mitigate moral distress in this care setting. In the first section of the MDDCS, we listed 28 different situations that may cause moral distress, with two corresponding 5-point response scales, for the participants to indicate the frequency of experiencing the situation (ranging from "has not happened over last year," to "daily"), as well as the magnitude of moral distress caused (ranging from "none at all" to "an extremely large amount"). The second section listed 15 potential effects of moral distress on the participant and asked participants to complete a 5-point response scale in order to capture the frequency of experiencing these effects over the last year (ranging from "never" to "daily"). The third section contained eight strategies that may reduce moral distress, and we asked participants to indicate on a 5-point scale how much they believed each strategy might reduce their feelings of moral distress (ranging from "none at all" to "an extremely large amount"). The final section consisted of three items. In the first of these three items, we asked the participant to assess how much moral distress had reduced their job satisfaction (on a 5-point scale ranging from "not at all" to "an extremely large amount"). In the second item, we asked about the extent to which moral distress caused the participant to feel like quitting her/his current job (using the same scale as above). Finally, in the third item we required a yes/no response to a question about whether or not the participant intended to quit her/his current job within the next year. Each of the sections also had an open comment area in case participants wished to add more details of their moral distress experiences.

Ethical considerations and approval

We obtained ethical approval for the study through the University of Lethbridge Human Subjects Research Ethics Committee, as well as the University of Alberta Research Ethics Board. Access to participating organizations was achieved through the provincial health authority's seniors' health leadership. Because of the personal nature of the data, we used locked and secured collection boxes at each site, and the data were anonymous. We stored completed surveys in a locked cabinet at the research team's office, and kept digital files in securely located, password-protected computers.

Data collection and analysis

Our development and implementation of the MDDCS instrument was informed by the work of Dillman, Smyth, and Christian (2014), whose method enhances construct validity and response rate for self-report instruments. We also enhanced our understanding of moral distress in these settings by engaging in an extensive literature review and undertaking intensive interviewing of nursing staff providing care to residents with dementia in continuing care settings. These activities led us to identify four major areas for measurement in the survey instrument: frequency of moral distress among nursing staff; causes of moral distress in the setting; effects of moral distress on nursing staff; and, strategies used to reduce moral distress. The four sections of the instrument reflecting these areas demonstrated Cronbach alpha's reliability statistics of .94, .92, .93, and .82, respectively. An overall Cronbach alpha for the MDDCS tool was .966.

Data collection entailed the completion of a paper-based survey; we did not collect any personally identifiable information on the survey, although general demographics were collected. Researchers made the surveys available to staff in the 23 facilities that had not participated in the pilot and instructed the staff to deposit the completed surveys in a locked collection box. Research assistants entered the data from the completed surveys, and the research team as a whole analyzed the data using statistical software (Statistical Package of the Social Sciences (SPSS), v. 21).

Findings

Demographics

We collected a total of 389 completed surveys for analysis, representing a 43.6% response rate. We classified sites as public (provincially funded) (31.6%), private for profit (8.7%), or not for profit (59.6%). Sites were also identified as being located in an urban (62.5%) or a rural (37.5%) setting. We included a range of residential sites that provided dementia care in the study: AL (54.5%), LTC (37.5), and facilities that offered a combination of both (8.0%). The gender distribution of participants was 92.5% female and 7.5% male, consistent with demographics in nursing caregivers (Estabrooks et al., 2015). Three role designations were represented by participants: RNs (18.9%), LPNs (13.9%), and HCAs (67.1%). This distribution was proportionate to the breakdown of providers by category in this sector in this province. The majority of staff participants had fewer than 10 years of experience in caring for people with dementia (60.7%); 28.9% of participants had 10 to 20 years of experience and 10.4% had more than 20 years of experience (see Table 1).

Table 1. Demographics of participants ($n = 389$) who completed the survey.

Characteristic	n	%
Long term care facility funding		
Public (provincially funded)	123	31.6
Private for profit	34	8.7
Not for profit	232	59.6
Geographical location of facility		
Rural	146	37.5
Urban	243	62.5
Type of facility		
Assisted living	212	54.5
Long-term care	146	37.5
LTC + AL	31	8.0
Gender of nursing staff		
Female	356	92.5
Male	29	7.5
Professional designation of nursing staff		
Registered nurse	72	18.9
Licensed practical nurse	53	13.9
Health care aide	255	67.1
Years of experience caring for people with dementia		
Less than 10 years	233	60.7
10 to 20 years	111	28.9
More than 20 years	40	10.4
Total	389	100.0

LTC: long-term care; AL: assisted living.

Overall findings of moral distress in nursing staff

Overall, we found that moral distress was indeed quite prevalent in the study participants. The majority of nursing staff (75.9%) reported experiencing situations that caused at least a moderate degree of moral distress, at least weekly, over the past year. Nursing staff rated the frequency and severity of 28 items that were identified as potentially causing moral distress. Table 2 highlights the most frequently experienced causes of moral distress identified by all participants, regardless of role designation. Table 3 highlights the 10 situations that caused the highest levels (severity) of moral distress. It is interesting to note that 6 of the 10 most frequently experienced events were also represented in the top 10 in terms of how distressing participants reported them to be (these items are indicated with an asterisk in both Tables 2 and 3).

A quadrant analysis was completed plotting standardized frequency (x-axis) against severity (y-axis) scores to graphically depict the 28 items in terms of four categories: infrequent and not severe; infrequent but severe; frequent but not severe; and frequent and severe (see Figure 1). A frequently occurring situation that was not considered to result in severe moral distress was "Telling the resident with dementia things that are not true so he/she won't get upset" (situation 4 in the MDDCS tool, depicted in the lower right quadrant of Figure 1). Of greater concern, however, were situations that were frequent and

Table 2. Ten most frequent situations that caused moral distress (scale 0–4).

Situation	Mean (SD)	% who experience daily or weekly
Telling the resident with dementia things that are not true so he/she won't get upset.	2.69 (1.32)	62.7
Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time.	2.54 (1.43)	59.7
*Seeing a low quality of life for residents with dementia because there are not enough activities.	2.56 (1.43)	59.4
*Seeing the care of residents with dementia suffer because there are not enough staff to do the work.	2.61 (1.28)	58.2
*Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them.	2.44 (1.41)	53.9
*Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies.	2.04 (1.28)	35.1
*Seeing the care suffer for residents with dementia because staff lack the knowledge and skills they need to provide dementia care.	1.83 (1.37)	32.4
*Having to provide care to aggressive residents with dementia without the supports I need to feel safe.	1.66 (1.46)	33.0
Having to work without the supports I need to prevent residents with dementia from hurting other residents.	1.54 (1.42)	28.5
Having to follow a family's wishes for care even if it doesn't seem the best for the resident with dementia.	1.92 (1.20)	31.3

Items with asterisk (*) were also identified as causing the most severe moral distress.

that resulted in severe moral distress. These items are depicted in the upper right quadrant of Figure 1, with the numbered items correlating to the situations identified in the MDDCS tool. The highest ranking item, causing both frequent and severe moral distress in all nursing staff, was situation 18: "Seeing the care of residents with dementia suffer because there are not enough staff to do the work." Working inwards from this outermost situation that causes the most frequent, and the most severe moral distress we see: (20) Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them; (19) Seeing a low quality of life for residents with dementia because there are not enough activities; (28) Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies; and, (9) Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time.

Differences in moral distress by role designation

We conducted a Kruskal Wallis test to evaluate whether there were differences between role designation and frequency and degree of moral distress. The means and standard deviations for each group are shown in Table 4 (frequency of causes of moral distress) and Table 5 (severity of moral distress). The difference between the groups was statistically significant for

Table 3. Ten situations that caused the most severe moral distress (scale 0–5).

Situation	Mean (SD)	% who experience large or very large amount
*Seeing the care of residents with dementia suffer because there are not enough staff to do the work.	3.84 (1.385)	71.9
*Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them.	3.44 (1.613)	59.6
Seeing care that does not show respect to residents with dementia.	3.29 (1.553)	56.6
*Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies.	3.38 (1.477)	53.8
*Seeing a low quality of life for residents with dementia because there are not enough activities.	3.30 (1.619)	52.7
Seeing residents with dementia living with pain because it is not treated appropriately.	3.04 (1.862)	53.1
Seeing poor care for a resident with dementia because of poor communication between staff members.	3.09 (1.612)	50.1
*Having to provide care to aggressive residents with dementia without the supports I need to feel safe.	2.89 (1.951)	49.7
*Seeing the care suffer for residents with dementia because staff lack the knowledge and skills they need to provide dementia care.	3.11 (1.676)	49.5
Seeing the care suffer for residents with dementia because physicians do not visit often enough.	3.11 (1.627)	49.2

Items with asterisk (*) were also identified as causing the most frequent moral distress.
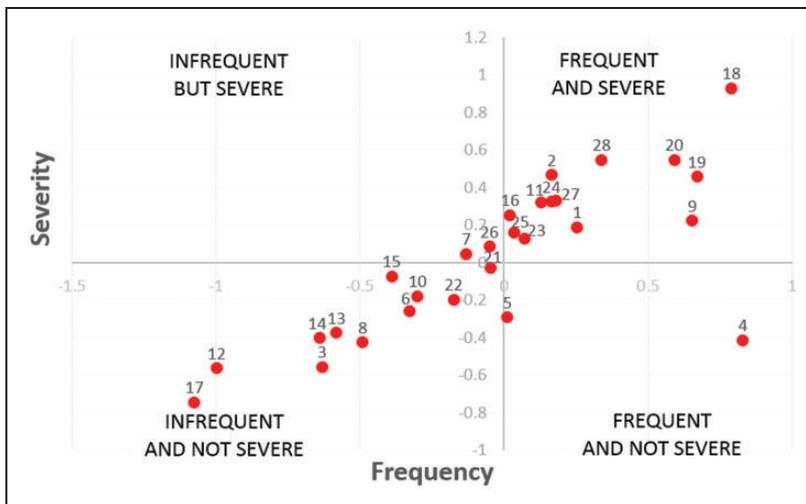

Figure 1. Standardized frequency scores plotted against standardized severity scores.

Table 4. Frequency of causes of moral distress by role designation (RN, LPN, HCA).

#	Situation	Role	n	% weekly or daily	Mean	SD	Test statistic	df	p	Post hoc test[a]
4	Telling the resident with dementia things that are not true so he/she won't get upset.	RN	72	41.6	2.15	1.329	18.589	2	<.001	RN < HCA
		LPN	53	60.4	2.58	1.379				
		HCA	249	69.5	2.90	1.253				
		Total	374		2.71	1.315				
8	Avoiding giving care to a resident with dementia because I am afraid the resident might hurt me.	RN	72	6.9	.53	.903	15.412	2	<.001	RN < HCA p < .001
		LPN	51	15.7	.96	1.248				
		HCA	252	18.2	1.16	1.303				
		Total	375		1.01	1.251				
9	Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time.	RN	71	32.4	1.59	1.430	42.20	2	<.001	RN < HCA p < .001 RN < LPN p < .007
		LPN	53	52.8	2.42	1.379				
		HCA	250	69.2	2.85	1.305				
		Total	374		2.55	1.422				
12	Not reporting what I believe is neglect or abuse of a resident with dementia because I'm afraid of causing trouble.	RN	72	4.2	.40	.899	12.185	2	.002	RN < HCA p < .009
		LPN	50	8.0	.42	.883				
		HCA	249	9.6	.73	1.064				
		Total	371		.63	1.020				
13	Not reporting problems with the care of residents with dementia because I feel no one listens anyhow.	RN	72	7.0	.60	1.030	9.857	2	.007	RN < HCA p < .021
		LPN	51	9.8	.65	1.055				
		HCA	246	15.8	1.05	1.316				
		Total	369		.91	1.245				
14	Going along with care for a resident with dementia that I don't agree with because of pressure from my coworkers.	RN	72	5.6	.54	.992	12.944	2	.002	RN < HCA p < .001
		LPN	51	9.8	.75	.956				
		HCA	250	15.8	1.04	1.202				
		Total	373		.90	1.148				
20	Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them.	RN	72	31.9	1.68	1.402	25.863	2	<.001	RN < HCA p < .009 RN < LPN p < .009
		LPN	53	49.1	2.45	1.353				
		HCA	250	61.6	2.65	1.357				
		Total	375		2.44	1.413				
22	Having to provide care that I think is against the wishes of the resident with dementia.	RN	72	8.4	.92	1.097	10.631	2	.005	RN < HCA p < .005 RN < LPN p < .039
		LPN	52	23.0	1.50	1.321				
		HCA	246	29.2	1.49	1.363				
		Total	370		1.38	1.326				
25	Having to provide care to aggressive residents with dementia without the supports I need to feel safe.	RN	72	18.0	1.13	1.288	13.476	2	.001	RN < HCA p < .001
		LPN	52	28.9	1.65	1.399				
		HCA	247	38.9	1.84	1.496				
		Total	371		1.68	1.468				

(continued)

Table 4. Continued.

#	Situation	Role	n	% weekly or daily	Mean	SD	Test statistic	df	p	Post hoc test[a]
26	Having to work without the supports I need to prevent residents with dementia from hurting other residents.	RN	72	19.4	1.19	1.307	6.395	2	.041	
		LPN	52	28.9	1.52	1.407				RN < HCA
		HCA	247	31.6	1.67	1.443				p < .035
		Total	371		1.56	1.421				
27	Seeing the care suffer for residents with dementia because families do not provide basic necessities.	RN	72	19.4	1.46	1.198	20.886	2	<.001	
		LPN	53	26.4	1.91	1.148				RN < HCA
		HCA	249	41.4	2.24	1.282				p < .001
		Total	374		2.04	1.282				

RN: registered nurse; LPN: licensed practical nurse; HCA: health care aides, personal support worker, or nursing assistant.
[a]Post hoc tests with Bonferroni correction reveal which designations had the more frequent causes of moral distress.

several items. In other words, RNs, LPNs, and HCAs differed in their experience of moral distress. Data indicate that, in general, both frequency and severity of moral distress increased with proximity to (investment of time in direct care at) the bedside. Overall, experiences of moral distress were more frequent and more severe for HCAs, followed by practical nurses and then RNs. Although there were a few exceptions, they were not statistically significant.

We also noted differences between nursing role designations in the reported frequency of situations causing moral distress. For example, experiencing moral distress as a result of seeing a low quality of life for residents with dementia because of a lack of resident activities was reported most frequently by RNs (M = 2.65; SD = 1.26) and LPNs (M = 2.83; SD = 1.31), whereas this situation ranked third in frequency for HCAs (M = 2.49; SD = 1.50). For HCAs, the two situations reported most frequently as causing moral distress were having to decide which resident to care for first when other residents needed them just as much, and having to rush the care of residents with dementia due to a lack of time. Our Kruskal–Wallis analysis determined that making difficult time allocation decisions was much more common for HCAs than for RNs, χ^2 (2, $N = 374$) = 42.2, $p < .001$. Similarly, we noted that having to rush resident care was more common in HCAs than in RNs, χ^2 (2, $N = 375$) = 25.863, $p < .001$. "Seeing the care suffer for residents with dementia because there was not enough staff to do the work" was reported as the second most frequent cause of moral distress for RNs, third in frequency for LPNs, and fourth in frequency for HCAs. However, while ranked differently, we did not find that the difference in means was statistically significant, indicating that all role designations identified insufficient staffing as a frequent cause of moral distress.

We found that the situation associated with the highest levels of moral distress for all participants was "seeing the care suffer for residents with dementia because there are not enough staff to do the work," which 58.2% of participants described as being a major source of distress either daily or at least once per week. Understaffing was also identified as the source of the most severe moral distress, rated by 71.9% of participants as generating a "large amount" or an "extremely large amount" of moral distress. RNs reported that "seeing care that does not show respect to residents with dementia" as the situation associated with the second highest levels of distress and "seeing residents with dementia

Table 5. Severity of moral distress by role designation (RN, LPN, HCA).

#	Situation	Role	n	Moderate, large or extremely large amount (%)	Mean	SD	Test statistic	df	p	Post hoc test[a]
8	Avoiding giving care to a resident with dementia because I am afraid the resident might hurt me.	RN	71	29.5	1.14	1.693	13.888	2	.001	RN < HCA $p < .001$
		LPN	50	40.0	1.80	1.818				
		HCA	245	45.3	2.02	1.840				
		Total	366		1.82	1.837				
9	Having to make a resident with dementia wait for care because another resident needs me just as much, at the same time.	RN	71	39.4	1.89	1.626	39.631	2	<.001	RN < HCA $p < .001$ RN < LPN $p < .008$
		LPN	50	70.0	2.82	1.438				
		HCA	245	73.8	3.25	1.312				
		Total	366		2.93	1.489				
12	Not reporting what I believe is neglect or abuse of a resident with dementia because I'm afraid of causing trouble.	RN	70	22.9	1.03	1.849	14.243	2	.001	RN < HCA $p < .013$ LPN < HCA $p < .009$
		LPN	50	20.0	.88	1.662				
		HCA	246	40.2	1.77	2.068				
		Total	366		1.51	2.008				
13	Not reporting problems with the care of residents with dementia because I feel no one listens anyhow.	RN	69	34.7	1.41	1.980	9.347	2	.009	RN < HCA $p < .042$
		LPN	50	32.0	1.38	1.872				
		HCA	245	46.2	2.07	2.079				
		Total	364		1.85	2.053				
14	Going along with care for a resident with dementia that I don't agree with because of pressure from my coworkers.	RN	70	25.7	1.17	1.744	12.718	2	.002	RN < HCA $p < .001$
		LPN	50	44.0	1.74	1.827				
		HCA	245	46.2	2.08	1.939				
		Total	365		1.86	1.916				
20	Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them.	RN	71	61.9	2.69	1.864	15.535	2	<.001	RN < HCA $p < .001$ RN < LPN $p < .020$
		LPN	50	88.0	3.70	1.266				
		HCA	247	81.7	3.60	1.550				
		Total	368		3.44	1.620				
22	Having to provide care that I think is against the wishes of the resident with dementia.	RN	71	42.3	1.68	1.688	9.240	2	.010	RN < HCA $p < .007$
		LPN	51	51.0	2.25	1.659				
		HCA	242	52.9	2.38	1.816				
		Total	364		2.22	1.787				
25	Having to provide care to aggressive residents with dementia without the supports I need to feel safe.	RN	72	56.1	2.11	1.968	15.624	2	<.001	RN < HCA $p < .001$
		LPN	51	64.8	2.86	1.970				
		HCA	246	68.7	3.13	1.879				
		Total	369		2.89	1.945				
26	Having to work without the supports I need to prevent residents with dementia from hurting other residents.	RN	72	51.5	2.24	2.017	7.584	2	.023	RN < HCA $p < .020$
		LPN	50	60.0	2.66	2.006				
		HCA	246	68.7	2.96	1.951				
		Total	368		2.77	1.987				
27	Seeing the care suffer for residents with dementia because families do not provide basic necessities.	RN	72	63.8	2.58	1.651	22.260	2	<.001	RN < HCA $p < .001$ RN < LPN $p < .003$
		LPN	50	86.0	3.60	1.195				
		HCA	248	81.4	3.54	1.411				
		Total	370		3.36	1.481				

RN: registered nurse; LPN: licensed practical nurse; HCA: health care aides, personal support worker, or nursing assistant.
[a]Post hoc tests with Bonferroni correction reveal which designations had the more severe experiences of moral distress.

living with pain because it is not treated appropriately'' as the third highest. The second most distressing situation reported by LPNs was ''having to rush the care of residents with dementia due to lack of time – even though I know it might upset them'' followed by ''seeing a low quality of life for residents with dementia because there are not enough activities'' as third. For HCAs, the situation that was associated with the second highest levels of moral distress was ''having to rush the care of residents with dementia due to lack of time, even though I know it might upset them,'' followed by ''seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies.'' Despite differences in rankings, the difference in means in the top three sources of severe moral distress were not statistically significant except for two items: having to rush care, and seeing care suffer because families do not provide basic necessities. Again using a Kruskal–Wallis test, we determined that moral distress associated with having to rush care was experienced more severely by HCAs and LPNs than by RNs, χ^2 (2, $N = 368$) = 15.535, $p < .001$. Similarly, seeing care suffer due to a lack of basic necessities was associated with the greatest moral distress in HCAs, followed by LPNs, and then RNs, χ^2 (2, $N = 370$) = 22.260, $p < .001$.

Effects of moral distress on nursing staff

Participants in this study reported that moral distress had negative psychological and physiological effects. At least weekly: 49.3% of participants reported feeling frustrated; 44.4% reported feeling physically exhausted; 41.6% reported feeling emotionally drained; 39% reported feeling powerless; and, 33.1% reported engaging in unhealthy behaviors as a result of moral distress. Three quarters (76.1%) of participants reported feeling frustrated at least on a monthly basis. On at least a monthly basis, participants (73.5%) also reported feeling emotionally drained or feeling physically exhausted.

We employed the Kruskal–Wallis test to evaluate whether the effects of moral distress differed as a function of role designation and found significant differences in the mean rank between the groups. We subsequently performed post hoc Mann–Whitney U pairwise comparisons with a Bonferroni correction and determined that LPNs and HCAs reported statistically significant stronger effects of moral distress than did RNs. Of note, HCAs were more likely than LPNs and RNs to not want to go into work ($\chi^2 = 8.019$, $p = .018$) or to want to call in sick ($\chi^2 = 8.805$, $p = .012$). LPNs and HCAs were more likely than RNs to feel emotionally drained ($\chi^2 = 10.157$, $p = .006$), physically exhausted ($\chi^2 = 15.866$, $p < .001$), or physically sick ($\chi^2 = 10.133$, $p = .006$). Effect size calculations for the differences between role designations and the effects of moral distress revealed that feeling emotionally drained and physically sick, and calling in sick, were medium to large size effects (.523, .525, .458, respectively). The effect size of ''feeling physically exhausted'' was very large (.822), indicating a profound difference between RNs and LPNs/HCAs.

Differences in intent to quit by role designation

Participants also indicated that the experience of moral distress negatively impacted job satisfaction. Approximately 40% of participants reported that moral distress reduced their job satisfaction a ''large'' or ''extremely large'' amount and another 35.6% reported that it had reduced their job satisfaction a ''moderate'' amount. More than one-quarter of participants (25.9%) reported that moral distress contributes to them wanting to quit

their job a "large" or "extremely large amount." However, 84.9% of participants did not intend to quit their jobs in the next year. We noted that proximity to the bedside appeared to be a predicting factor of intent to quit within the next year. Fifty-three percent of HCAs reported that frequent and severe experiences of moral distress contributed a moderate, large, or extremely large amount to their intent to quit their jobs, compared to only 40.3% of RNs and 41.5% of LPNs. The rate of intention to quit due to moral distress was highest among HCAs (15.4%).

In order to determine if there was a small number of core factors underlying the reported effects of moral distress, we conducted a factor analysis. We found that some of the variables were skewed but were not transformed due to the same response options being used for each variable. We observed no univariate or multi-variate outliers. Principal components extraction was used prior to factor analysis to estimate the number of factors, presence of variable outliers, absence of multi-collinearity and singularity, and factorability of the correlation matrix. Three factors were extracted using the Maximum Likelihood procedure and rotated using a Varimax rotation procedure. The factor loadings yielded four interpretable factors: psychological distress (Factor 1); physiological distress (Factor 2); total exhaustion (Factor 3), and avoidance (Factor 4). The psychological distress factor (feeling angry, powerless, guilty, sad, or frustrated) accounted for 18.0% of the item variance. The second factor, the physiological factor (losing sleep, feeling physically sick, or having bad dreams), accounted for 14.0% of the item variance. The third factor, total exhaustion (feeling emotionally drained or physically exhausted), accounted for 12.7% of the variance. The fourth factor, avoidance (not wanting to go into work, calling in sick), accounted for 10.9% of item variance.

We also applied a Kendall tau b correlation to examine the strength of the relationship between the intent to quit in the next year and the severity of effects participants experienced, as grouped in the factor analysis. We noted a significant positive correlation for all factors, indicating that negative effects of moral distress within the individual staff member were significantly associated with intent to quit within the year. Factors correlated with intent to quit within the next year were: psychological distress ($\tau = -.186$, $p < .001$); physiological distress ($\tau = -.143$, $p = .001$); total exhaustion ($\tau = -.248$, $p < .001$); and, avoidance ($\tau = -.265$, $p < .001$). In other words, staff who reported more severe and more frequent effects of moral distress were more likely to express an intent to quit their jobs within the next year. While the effect sizes of these factors are not high, we assert that taken together, these factors are strongly suggestive of a pattern of distress response that contributes significantly to creating an intent to leave the workplace.

Discussion

Our study is one of the first published studies to report that moral distress is a prevalent experience for nursing staff who care for people living with dementia, and our findings suggest that this problem is an important but under-researched area of dementia care. A particularly striking finding from this study is that there is substantial overlap of situations that cause both frequent and severe moral distress. To have frequent exposure to experiences that cause severe moral distress is cause for serious concern. The authors believe that frequent, severe moral distress is flagging a system problem in LTC and AL settings. Taken together, the six items associated with severe moral distress on a frequent basis suggest a resource deficit in LTC and AL settings (not enough staff to provide the

desired level of care; lack of recreational therapy and other activity resources; lack of knowledge, training, and other supports in resident care). The participants also reported a lack of time resources (having to rush the care of residents); however, this item may also be viewed as related to understaffing—leading to hurried care. Participants in our study also reported a lack of material resources (family not bringing in supplies for the resident's well-being and comfort; lack of activities). A discussion of the factors driving this resource deficiency is beyond the scope of this paper; however, it is clear that nursing staff of all designations report being acutely affected by resource deficiency.

The most frequently reported source of moral distress reported by all three role designations was the same: "Seeing care of residents with dementia suffer because there are not enough staff to do the work." Understaffing has been identified as a consistent problem in LTC settings (Brazil, Maitland, Ploeg, & Denton, 2012; Sales et al., 2012). When staffing is not sufficient, time pressures result in many care tasks being left undone—including oral care, bathing, toileting, and even feeding (Armstrong, Armstrong, Banerjee, Daly, & Szebehely, 2011; Daly, Banerjee, Armstrong, Armstrong, & Szebehely, 2011). Others have also noted that having to ration resident care due to staff and time constraints within LTC settings results in unfinished and missed care; as a result, nursing staff can experience moral distress, decreased job satisfaction, and increased intent to quit (Jones, Hamilton, & Murry, 2015).

Other frequently reported sources of moral distress in our study were unique to nursing role designations. For example, RNs' second leading cause of frequent moral distress was "Seeing care that does not show respect to residents with dementia." This item was not identified by LPNs and HCAs. Conversely, LPNs and HCAs reported their second most frequent cause of moral distress as "Having to rush the care of residents with dementia due to lack of time—even though I know it might upset them." HCAs' third most frequent cause of moral distress, which was not identified by LPNs or RNs, was reported as "Seeing the care suffer for residents with dementia because families do not provide basic necessities such as clothing and other supplies." This is perhaps not surprising given the proximity to the bedside and amount of time spent in daily resident care by the HCA, a caregiver who is likely most intimately acquainted with the residents' daily personal needs.

Understaffing has been reported as having multiple negative effects, the most obvious being less time for care (Chin, 2013; Duffield et al., 2011; Horn, Buerhaus, Bergstrom, & Smout, 2005), which in turn results in moral distress, as found in our study. Working in conditions with insufficient staff resources has also been found to contribute to: compassion fatigue and burnout (Maiden, 2008; Zhu et al., 2012); medication errors (Maiden, 2008); increased infection risk (Kiekkas, 2013), including *E. Coli* (R. Banerjee et al., 2013; Burgess et al., 2015); and, untimely patient mortality (Aiken et al., 2014). Understaffing and the resulting moral distress also negatively impacts work life and well-being (Jones et al., 2015), an observation supported by our findings. In our study, HCAs were much more likely to not want to go into work and even call in sick to avoid going into work, a finding also supported in another Canadian study by Armstrong et al. (2011). Others have noted that although workload itself is not a direct cause of staff turnover and intention to quit, moral distress arising from role ambiguity and role conflict is (Rai, 2015). In our study, although moral distress was reported as making a significant contribution to job dissatisfaction for HCAs, over 80% of these workers did not plan to quit their job in the next year. This intention to stay working in this capacity, despite ongoing hardships and stress, may indicate that the rewards of service work outweigh the

drawbacks (Chenoweth et al., 2010; Rai, 2015), that job satisfaction prevails and solidifies commitment to the organization (Rai, 2012), or that a sense of altruism prevails in the decision to stay (Chenoweth, Merlyn, Jeon, Tait, & Duffield, 2014). It may also be the case that many workers are unable or presently unqualified to seek employment in other roles or settings—and are essentially "trapped" by economic considerations and limited opportunities.

Nursing staff in our study also reported moral distress as a result of seeing a low quality of life for residents with dementia because of a lack of activities. MacDonald (2006), in a study exploring perceptions of family and staff in LTC, also noted the dearth of leisure opportunities within the LTC environment, a finding supported by the work of Wood, Womack, and Hooper (2009) and Benjamin et al. (2011). Armstrong et al. (2011) noted that the structural realities of LTC often mean social care of residents is neglected due to workload issues. Activity involvement has been noted in the literature as boosting quality of life for people with dementia (Shippee, Henning-Smith, Kane, & Lewis, 2015; Smit, de Lange, Willemse, Twisk, & Pot, 2016; Wood et al., 2009) and yet it would seem that these opportunities are often inadequate in many residential care environments, an observation that is supported by the results of our study.

Nursing staff also experienced, and feared, being hurt by residents with dementia. Violence against HCAs in long-term settings has been described in the literature, with rates higher in staff who are closest to the bedside, namely HCAs (Armstrong et al., 2011; A. Banerjee et al., 2008; Daly et al., 2011). A. Banerjee et al. (2008), in their survey of LTC workers, found that 89.7% of HCAs experienced violence from residents while at work.

We also noted that different types of nursing staff reported different sources of moral distress to different degrees. In short, proximity to the bedside was associated with more severe and more frequent experiences of moral distress, and increasing distance from the bedside (i.e. the RN role) was associated with less frequent and less severe experiences of moral distress. Unfortunately, the current study does not shed light on why the frequency and severity of moral distress increases with proximity to the bedside. However, the findings of this study lead us to hypothesize that those closest to care in this setting are caught in a double-bind: they see and experience the deficits in care resources most directly, and yet are the least able to advocate for change because of their relatively low position in the health care hierarchy.

Corley (2002) has proposed a theory of moral distress that includes several antecedents to the experience of moral distress. One of these antecedents that has relevance to the present discussion of proximity to the bedside is autonomy. Corley (2002) suggested that if a caregiver has moral sensitivity and commitment, but lacks either moral courage or moral autonomy to take steps to amend the issue, s/he will suffer moral distress. Edvardsson et al. (2009) similarly found that lower work autonomy was associated with higher job strain in residential dementia care staff. Conversely, having the freedom to decide how and what to accomplish in one's daily work was associated with much lower job strain (Edvardsson et al., 2009). Looking at it another way, the more education a health care worker has—and thus professional autonomy conferred by virtue of degrees and registration—the less moral distress they may experience. Thus, while on one hand it may appear that higher levels of education are a protective factor against the experience of moral distress, we suggest that it is more likely that higher education makes it more likely that a caregiver will move farther away from the bedside—i.e. it is proximity to the bedside that in fact constitutes a considerable risk factor for moral distress. Indeed, within registered nursing, higher

education is associated with greater autonomy and increased job retention (Rambur, McIntosh, Palumbo, & Reinier, 2005). However, whether this finding can be extrapolated to non-RN roles—including LPNs and HCAs—is not known.

In our study, we explored the experiences—in frequency and severity—of moral distress in nursing staff of residents with dementia in LTC. Although we asked individual nursing staff to report their moral distress, we do not believe solutions lie solely at the individual level. Rather, we believe that the experience of moral distress is a symptom of a greater problem within the continuing care sector, and that the most productive solutions can be arrived at by framing moral distress as essentially a structural concern. Health care providers can be viewed as ''weak or failing when moral distress is constructed as primarily an individual concern'' (Varcoe, Pauly, & Webster, 2012, p. 53), and yet moral distress

> . . . is not merely a problem of individuals but . . . is the canary in the coal mine that alerts us to broader contextual factors that impact the abilities of nurses and other health care providers to enact ethical practice in the best interests of those for whom they care. (Varcoe et al., 2012, p. 54)

Thus, we believe that an important area for future research lies in exploring the influence of some of the strategies suggested by nursing staff as potentially useful in mitigating moral distress. However, it must be said that our findings most strongly suggest that resource deficits are contributing significantly to creating a morally distressed workforce in the continuing care sector, and that solutions for addressing these deficits are a priority in addressing the issue of moral distress.

Limitations

Our study was limited to one geographic area and one point in time, and vulnerable to the biases that come with self-report and participants self-selecting into the study. Additionally, there was no comparison group (e.g. acute care) to demonstrate that the experiences in LTC are unique. The sample, which was relatively small, was characterized by unequal group sizes (e.g. role designation) and as such comparisons must be made with caution.

Conclusion

This study adds to the existing literature on dementia care by elucidating the sources, pervasiveness, consequences, and role differences in the experience of moral distress in nursing providers of dementia care in residential care settings. In particular, this study highlights the distressing situations arising when resources are challenged. That the consequences are felt most acutely by those that are closest to the bedside is of concern and invites an urgent consideration of how we are supporting those who are providing the bulk of direct care for some of the most vulnerable citizens in society. Further research is needed to inform potential solutions at the individual staff member level and at the system level—solutions that are focused on supporting, valuing, and adequately preparing the continuing care workforce to provide compassionate and high-quality dementia care.

Colin Zieber, executive director of seniors health in the South Zone, who ensured the research went ahead.

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