

Original Article


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Abstract

Objectives. Moral distress is associated with adverse outcomes contributing to health-care professionals' worsened mental and physical well-being. Medical social workers have been frontline care providers throughout the COVID-19 pandemic, and those specializing in palliative and hospice care have been particularly affected by the overwhelming numbers of those seriously ill and dying. The main objectives of this study were (1) to assess palliative and hospice social workers' experiences of moral distress during COVID-19 and (2) to identify and describe participants' most morally distressing scenarios.

Methods. Using a mixed-methods approach, participants completed an online survey consisting of the Moral Distress Thermometer (MDT) and open-ended text responses.

Results. A total of 120 social work participants responded to the study, and the majority of participants (81.4%) had experienced moral distress with an average MDT score of 6.16. COVID-19 restrictions emerged as the main source of moral distress, and an overlap between the clinical and system levels was observed. Primary sources of moral distress were grounded in strict visitation policies and system-level standards that impacted best practices and personal obligations in navigating both work responsibilities and safety.

Significance. In the first year of the COVID-19 pandemic, palliative and hospice social work participants indicated high levels of moral distress. Qualitative findings from this study promote awareness of the kinds of distressing situations palliative and hospice social workers may experience. This knowledge can have education, practice, and policy implications and supports the need for research to explore this aspect of professional social work.

Introduction

There have been increasing concerns about health-care providers' mental health and well-being since the onset of the COVID-19 pandemic (Lai et al. 2020; Wallace et al. 2020). Necessary hospital restrictions, ongoing personal risk, mortality rates, and insufficient resources have put providers in stressful and ethically challenging situations (Morley et al. 2020). Emerging research on health-care providers during the COVID-19 pandemic revealed high rates of depression, anxiety, and insomnia and a growing concern for heightened moral distress (Cacchione 2020; Hines et al. 2020; Morley et al. 2020). Moral distress is the experience when a health-care provider cannot fulfill professional responsibilities or do what they are morally or ethically compelled to do (Jameton 1984). As a result, the providers may experience poorer mental health, increased burnout, and a higher rate of leaving the profession (Lamiani et al. 2017, 2018; Rushton et al. 2015). Previously identified sources of moral distress, primarily researched in the nursing profession, include factors from the system (e.g., hospital policies, excessive documentation, lack of administrative support, and staffing shortages), team (e.g., inconsistent or inadequate communication, witnessing colleague incompetence, and bullying behaviors), and clinical care levels (e.g., administering intensive care without benefit, end of life, and acute care settings) (Epstein et al. 2019; Lamiani et al. 2017). Researchers and clinicians suggest that providers may experience different levels of moral distress based on personal or employment characteristics such as age, years of experience, education, or licensure; however, findings have been inconclusive (Lamiani et al. 2017). More consistently, there is supportive evidence for higher moral distress scores for clinicians depending on work settings, such as in hospital intensive care units, where patients may be sicker and require more intensive therapies triggering distressing situations (Epstein et al. 2019; Lamiani et al. 2017).

Research in other health-care professions is growing, with more studies including other team members such as physicians, pharmacists, respiratory therapists, and social workers (Lamiani et al. 2017). The need for medical social workers is expected to grow 14% between 2019 and 2029

(U.S. Bureau of Labor Statistics 2021), and how the COVID-19 pandemic has impacted social work turnover and demand is currently unknown. Furthermore, medical social workers' skills will be needed as the US population ages and health-care needs become increasingly complex. While there has been substantial documentation about moral distress in nursing, understanding moral distress in the social work profession has only begun. Thus far, research has focused on medical social workers in countries such as Canada (Fantus et al. 2017), Australia, Korea (Fronek et al. 2017), Israel (Lev and Ayalon 2018), and, most recently, the United States (Guan et al. 2021).

To date, researchers have suggested that social workers experience similar sources of moral distress as other health-care professionals due to insufficient managerial support, high caseloads, witnessing unethical behavior, and lack of institutional resources for their patients (Fantus et al. 2017; Lev and Ayalon 2018). Medical social workers' roles vary from predominately clinical (e.g., counseling, assessment, and treatment) to case management (e.g., identifying resources, discharge planning, and care coordination) and oftentimes both (Stanhope 2015). Moral distress around clinical situations involving patients and families may be expected. For example, Guan et al. (2021) study of oncology social workers, those who provided direct care and worked in inpatient and outpatient settings had higher moral distress than those in strictly outpatient settings or administrative departments. As explored in other professional groups, personal characteristics may also impact how intensely or frequently moral distress is experienced. Younger providers had higher moral distress scores in the same sample of oncology social workers; those with under 2 years of experience had higher scores than those with 2–5 years of experience (Guan et al. 2021).

Social workers' conduct is guided by an ethical code that prioritizes advocacy for fair treatment, justice, and self-determination while protecting patients from harm. Thus, the way they experience moral distress may result from incongruence between their professional values and ethics and the needs of the hospital organization or disease-focused treatment. We see value incongruence as a source of distress in nonsocial workers (Lamiani et al. 2018), but social workers may experience this more commonly than nonsocial workers due to their lack of autonomy, hierarchical health settings, and professional code of ethics. In one qualitative study of Korean and Australian hospital social workers, social workers were identified as being in "intractable situations where they were asked to break the rules and act against their code of ethics by those in positions of greater authority" (Fronek et al. 2017, 674). Social workers' unique hierarchical position in most health-care settings may contribute to the frequency and intensity of this experienced distress.

The growing complex health needs and an aging population have also increased the demand for palliative and hospice care (National Coalition for Hospice and Palliative Care (NCPC) 2018). As a result, the role and utility of palliative and hospice social workers have grown, and they are considered integral members of interdisciplinary teams across the continuum of care (e.g., acute care, post-acute care, and home settings) (National Coalition for Hospice and Palliative Care (NCPC) 2018). Like medical social workers, they are specialists who assess the needs, coping, culture, and dynamics of the individual and family, intervene during discord, assess and treat mental health, and identify and facilitate resources (National Coalition for Hospice and Palliative Care (NCPC) 2018). Furthermore, as frontline workers, hospice and palliative social workers were present in those health-care settings

most affected by the COVID-19 pandemic; thus, understanding their experiences of moral distress during this extraordinary time is vital. This study is the first to explore palliative and hospice social workers' moral distress. This study aimed to explore the experience of moral distress for palliative and hospice social workers during COVID-19 and invite first-hand encounters of moral distress.

Methods

Participants

This exploratory and descriptive study sampled current palliative and hospice social workers employed during the COVID-19 pandemic (June 2020 to August 2020) using an anonymous online questionnaire delivered via an online survey and data management program (Qualtrics, Provo, UT). Participants were recruited from a national social work hospice and palliative organization (Social Work Hospice Palliative Care Network) and a palliative and hospice dedicated email listserv (SW-EOL Listserv). The organization included 1,020 members and the listserv included approximately 845 members at the time of the survey, some of which likely overlapped. Overall, a total of 169 responses were recorded, but due to the snowball sampling method, a response rate could not be reported. After data cleaning and screening, the final sample included 120 participants. The survey link was open for 7 weeks, from June 24 until August 12, 2020. The protocols and procedures used in this study were reviewed and approved by a university institutional review board.

Materials

For this study, we administered an online questionnaire that included sociodemographic questions, the Moral Distress Thermometer (MDT), and an open-text response related to their most morally distressing experience. Participants answered sociodemographic questions related to participants' gender, age, ethnicity, region of the United States, employment status, work setting, education, licensure, and certifications. The questionnaire's content was developed based on (1) existing literature pertaining to social workers' moral distress (Fantus et al. 2017; Lev and Ayalon 2018; Wocial and Weaver 2013) and (2) the primary investigators' experience with palliative and hospice in clinical settings. The survey research used open-ended questions to gain a richer understanding of participants' experiences (Vaterlaus et al. 2021), and this was supported by the Tailor Design Method, which guides quality survey development (Dillman et al. 2014).

The MDT is a single-item visual analog scale (0 = no distress, 10 = highest distress) used to assess perceived levels of moral distress and served as the primary continuous outcome variable (Wocial and Weaver 2013). The scale allowed participants to report their current level of moral distress across a continuum of values using an interactive graphic slider. They were instructed to drag the indicator to the position on the scale representing their current distress level. While reliability cannot be measured in the single-item scale, the MDT has demonstrated convergent validity with a valid measurement of moral distress, the Moral Distress Scale, in a sample of 529 inpatient hospital nurses (Wocial and Weaver 2013).

Procedure

After obtaining informed consent, participants were provided with a general description of moral distress consistent with

Jameton's (1984) operationalization, which read: "Moral distress occurs when you believe you know the correct thing to do, but something or someone restricts your ability to pursue the right course of action." Next, participants were asked if they experienced situations that caused moral distress during the pandemic (coded as yes/no). Using branch logic, participants who answered "no" answered only sociodemographic questions. Participants who answered "yes" were asked to complete the MDT and follow-up questions about their experiences. This study analyzed responses to one of the open-ended questions that asked participants to "describe their most morally distressing experience during the COVID-19 pandemic."

Analytic strategy

We used IBM SPSS (version 27) to describe the sample and if there were any mean differences with moral distress (IBM Corp 2020). We conducted independent *t*-tests for dichotomous variables: (1) gender (male/female), (2) employment status (full-time/part-time), (3) certification (Advanced Palliative Hospice Social Worker Certification [APHSW-C]/advanced certified hospice and palliative social work), (4) ethnicity (White/other), (5) education (Master of Social Work [MSW]/other), (6) licensure (independently licensed/other), and setting (palliative/hospice). For categorical variables, we conducted an analysis of variance for (1) age (25–34/35–44/45–54/55+) and (2) the US region (Northeast/Midwest/South/West). Participants with >75% of data missing were removed. Assumption checking was conducted for outliers, normality, and homogeneity of variances, with no major violations observed.

Qualitative methods, and the main focus of our study, were used to analyze social work participants' descriptions of their most morally distressing experience during the COVID-19 pandemic. We examined the open-text responses to gain a more in-depth understanding of how intensely the US social workers experienced moral distress during the first 6 months of the pandemic. The texts were exported to SPSS and then copied into Microsoft Word utilizing the *Comments* function to track themes. Authors independently identified emerging themes and held frequent discussions to resolve disagreements through an iterative process.

Results

The sample ($N = 120$) comprised 89.2% females, with just over half of the participants between 35 and 54 years old. Around 18% ($n = 22$) had not experienced moral distress during the COVID-19 pandemic at the time of the survey. The participants were primarily White (89.2%), were employed full-time (87.5%), and had an MSW (92.2%). More than half of the participants worked in palliative care (68.8%) and are independently licensed (68.4%). Most participants who indicated additional certification reported having an APHSW-C (see Table 1 for complete demographics).

Intensity of moral distress during COVID

The MDT scores of this sample ranged from a minimum of 1.90 to a maximum of 10, with a mean score of 6.16 ($SD = 1.86$). This score increased with age as the lowest mean was from the youngest age group of 25 to 34-year-olds and the highest from those aged 55 to 64. Those in palliative care outpatient settings had the highest ratings on the MDT, even higher than those working in home settings. There were no significant group differences with any of the

variables (region of the country, education level, age, gender, etc.). When asked if the participants experienced moral distress during the COVID-19 pandemic, the majority (81.4%) indicated that they had experienced a situation that resulted in moral distress.

Most morally distressing event

The overarching theme of the open-ended responses was how the COVID-19 pandemic restrictions impacted clinical care and system levels. COVID-19 restrictions (e.g., visitor restrictions, quarantines, personal protective equipment (PPE), etc.) permeated the hospital system and surfaced as the primary cause of moral distress. We observed a connectedness among the levels of care where the national public health response to the spread of the COVID-19 virus through distancing and isolation and use of PPE influenced health-care decision-making policies and actions (e.g., resource allocation, visitor restrictions, use of PPE, etc.) and trickled to impact clinical care. Participants shared that there was not a single source of distress but rather a complex entanglement that reflected their reality of navigating patient care during the COVID-19 pandemic. Notwithstanding the interconnected relationships, we extracted three themes that reflect the *most* morally distressing sources: clinical care, system, and personal impact.

Clinical care

Most participants shared their experiences of navigating strict visitation policies that constricted their ability to provide and support quality evidence-based clinical care. Many participants discussed the constraint of having no options to mitigate the stress, burden, and suffering their patients were experiencing due to institutional protocols. Changes in resource access left many people without their usual familiar support systems and processes.

"Visitor restrictions – our hospital implemented visitor restrictions; thus our patients could not have visits from their family while hospitalized. I found this to be particularly challenging especially for our palliative care population – who are seriously ill and at EOL [sic]."

"No visitors are allowed so patients are suffering from isolation on another level that was not previously there before"

The COVID-19 restrictions contributed to participants witnessing their patients and families being unable to make value congruent care decisions at the end of life with no ability to alleviate their suffering,

"...In general, limits to visitors to say "good-bye" to loved ones. With limited visitation, limited first-hand experience of family before having to have life and death discussions. They aren't ready to withdraw life support because they haven't been with their loved ones."

Restrictions prevented clinicians from feeling as though they were adequately providing clinical care, including facilitating discussions, effective communication, and demonstrating compassion. Social workers felt they could not provide adequate care due to barriers from PPE, but they also witnessed suffering they could not help alleviate.

"Being unable to visit, use healthy touch to show compassion to family in need of emotional support for crisis."

"Not being able to provide care as I am capable and trained to do."

System

The impact of COVID-19 restrictions greatly impacted available resources and care options for patients and their families and contributed to a visceral response to the crisis, threatening not just

Table 1. Sociodemographic characteristics of participants and group comparisons

Characteristic	$N_{\text{total}} = 120$		MDT score ^a		t-test		ANOVA	
	N (%)	Mean (SD)	n	t-test (df)	p -value	F statistic (df)	p -value	
Gender								
Female	107 (89.2)	6.22 (1.90)	89	-.915 (96)	.363			
Male	13 (10.8)	5.62 (1.38)	9					
Age								
25–34	21 (17.5)	5.78 (1.74)	20			.349 (3, 94)	.790	
35–44	36 (30)	6.24 (2.00)	28					
45–54	29 (24.2)	6.23 (1.92)	22					
55+	34 (28.3)	6.31 (1.81)	28					
Ethnicity								
White	107 (89.2)	6.20 (1.87)	88	.614 (96)	.541			
Other	13 (10.8)	5.82 (1.83)	10					
Employment status								
Full-time	105 (87.5)	6.09 (1.79)	88	-1.108 (96)	.271			
Part-time	15 (12.5)	6.78 (2.41)	10					
Education^b								
MSW	107 (92.2)	6.22 (1.81)	89	1.229 (94)	.222			
Other	9 (7.8)	5.31 (2.62)	7					
Setting to provide social work services^c								
Palliative care (inpatient, outpatient, and home-based)	77 (68.8)	6.24 (1.66)	65					
Hospice care (home-based, respite, and inpatient)	35 (31.3)	5.87 (2.41)	27	.715 (36.68)	.479			
Licensure^d								
Independently licensed	80 (68.4)	6.24 (1.91)	67	.781 (94)	.437			
Other	37 (31.6)	5.92 (1.81)	29					
Certification^e								
APHSW-C	28 (58.3)	6.56 (1.75)	23	1.867 (40)	.069			
ACHP-SW	20 (41.7)	5.45 (2.12)	19					
Work location/Region in USA^f								
Northeast	21 (18.4)	5.95 (1.76)	17			.100 (3, 90)	.960	
Midwest	17 (14.9)	6.22 (2.43)	16					
South	23 (20.2)	5.99 (1.60)	18					
West	53 (46.5)	6.18 (1.80)	43					
MD presence^g								
Yes	96 (81.4)	6.18 (1.87)	96					
No ^h	22 (18.6)							

MDT = Moral Distress Thermometer; MD = moral distress; MSW = Master of Social Work; APHSW-C = Advanced Practice Hospice and Social Work Certification (exam-based certification); ACHP-SW = Advanced Certified Hospice and Palliative Social Work (non-exam-based certification).

^aDue to missing data, the N 's for the MDT scores are different as not everyone who answered the demographic questions, also answered the MDT question.

Missing data:

^b3.3%.

^c55%.

^d2.5%.

^e60%.

^f5%.

^g1.7%.

^hDid not answer MDT question.

patients but also the broader community. For instance, participants noted:

“Loss of options; I feel like I’m promoting something I cannot deliver. Medicare wants us in the homes, yet I wonder what they’re thinking with such high numbers of COVID.”

Not only did in-home care create challenges, but concerns around how the hospital was handling restrictions in response to infection rates created distress around whether adequate care was being provided.

“Hospital quickly reopening to book surgeries that bring in the majority of the income and staff are being dismissive about the pandemic. The hospital is more focused on beds and money than actual care.”

Participants also shared distress around decisions that may have contributed to inequitable or unfair treatment.

“Visitor policy was not consistent left to nursing floors and there were many cases of implicit bias.”

“Racial disparity and what feel like hypocritical actions related to the med system’s stated mission.”

Social work participants’ ethical commitment to the well-being of society and team members was as important as their commitment to their patient’s well-being. This dissonance left participants with the experience of moral distress as they could not do what they needed to do for either.

“Generally, protecting vulnerable populations from potential exposure to infection, but not able to address needs for increased socialization, family and touch, which are critical to quality of life for those with limited time left.”

“I have also been distressed by the demands placed on my physician colleagues who have been caring for the COVID patients – feeling as though leadership doesn’t understand the demands or the toll it’s taking on them.”

“Nurses and aides are worried about bringing the virus home, I am not able to reassure them.”

Personal impact

What also emerged from these responses was the impact the COVID-19 pandemic had on participants’ internalized sense of safety and well-being. Clinicians struggled to balance being present and available at work while also protecting selves and others. The work of palliative and hospice social work is deeply personal and reflective; the constraint of being unable to attend to one’s own needs and worries about safety surfaced as moral distress. As one participant shared,

“I have felt obligated to return to inpatient work sooner than I felt emotionally ready.”

“Wanting to be able to comfort patients by being physically present and unable to feel capable of doing this safely.”

“Torn between wanting to be present in the hospital to support my team and patients and wanting to be home working remote for my own safety and the safety of my family.”

“I have also experienced a sense of isolation from my friends and family who are having a very different experience of the pandemic (ie, they have been largely quarantined at home with their families, working from home or not working, rarely in public places, etc. while I have been working full-time in as a frontline health-care worker with a high degree of risk).”

Discussion

This study is the first to explore moral distress and use the MDT in a sample of palliative and hospice social workers. Intentionally brief to encourage participation and screen for levels of moral distress in a given moment, palliative and hospice social workers’ moral distress on the MDT was high. In comparison, using the same instrument with a sample of inpatient nurses before the COVID-19 pandemic, the average moral distress score was approximately half of the current study’s (Wocial and Weaver 2013). There were no significant group differences across personal and employment characteristics in the present study, potentially indicating that moral distress was experienced similarly despite differences in education, licensure, work setting, etc. Existing literature is inconsistent regarding whether personal or employment characteristics impact moral distress (Epstein *et al.* 2019; Guan *et al.* 2021; Lamiani *et al.* 2017). While our ability to compare with other studies is limited due to differing measurements, future research should investigate larger samples and more complex modeling inclusive of other morally related concepts such as moral sensitivity, wisdom, and emotional intelligence to elucidate the relationships among age, education, or years of experience.

Despite data collection during a stressful and chaotic period of time during the initial wave of the COVID-19 pandemic, the participants took the time to answer open-text responses about their experiences elaboratively. Qualitative findings from this study showed the impact of the COVID-19 restrictions as the dominant contributor and how this impact affected clinical, system, and personal experiences of distress. Participants struggled with the need to provide quality care, as best they could, while also trying to protect themselves, their families, team members, and the community from infection. Ulrich (2014) suggested this scenario as an ethical task, and participants felt they could not do either, which was identified as deeply morally distressing. Social work participants also experienced distress as their commitment to providing the best clinical and equitable care, system-wide, was in question. While participants were not necessarily in authoritative positions to decide or implement institutional protocols related to restrictions, they identified that witnessing others provide perceived discriminatory or unfair treatment was morally distressing. This finding has implications for how moral distress interventions are implemented. Understanding how views are intertwined, individual, work, and external, may offer an opportunity to work on these issues at the political, organizational, and educational levels, in addition to the personal, so commonly suggested (e.g., emotional intelligence, education, debriefings) (Lamiani *et al.* 2017).

As we continue to build on our understanding of moral distress, research on how moral distress is experienced differently across disciplines is needed and may help generate more solutions (Epstein *et al.* 2019). Interdisciplinary care may also provide opportunities to openly discuss shared cognitive and emotional impacts (Cacchione 2020). Promoting shared language around moral distress would be beneficial; however, the variations among professionals may require many levels of understanding to inform suggestions and strategies.

Limitations

There are cautions when interpreting the findings of this study that are worth mentioning. First, the total population size is unknown, and there is a risk of self-selection bias as those with moral distress or high levels of moral distress may have been more likely

to take the survey. Further, while the MDT has been utilized in research and practice (Wocial and Weaver 2013), it has not yet been validated in a sample of social workers, so future research validating this instrument with other disciplines is necessary. Our study had limited representation by Black, Indigenous, people of color, and non-female identifying persons. Ongoing research is needed to understand how moral distress is experienced by persons marginalized by sociopolitical structures. Our aim to provide information about how groups compare with respect to the MDT was for descriptive purposes, and inferential value is encouraged to be interpreted with caution due to the potential for inflated error by conducting multiple *t*-tests. However, as none of our tests resulted in significant findings, the risk of identifying a “false positive” is null. Nevertheless, larger samples with increased power to identify possible group differences is encouraged in future studies.

Notwithstanding these limitations, these exploratory findings provide preliminary insight into a sample of palliative and hospice social workers’ experience of moral distress during the COVID-19 pandemic. The study’s findings raise awareness around morally distressing scenarios that would benefit from more robust research with extended qualitative analysis. Further exploration could help distinguish whether morally distressing situations are new, occurring more frequently, amplified, or if there is so much unresolved moral distress that there is a new unmanageable baseline.

Conclusions

Raising the voices of health-care workers as they described moral distress during COVID-19 reminds us of the urgency to support, see, and hear their concerns (Shanafelt et al. 2020). Epstein et al. (2020) suggest that we work toward a moral community, undertaking the obligation to provide all levels of support to people who work in health care, weaving together individual, team, and structural solutions. As we learn more about moral distress and how it impacts all health-care professionals, a moral community is created by conjoining individuals and institutions toward a shared moral purpose (Epstein et al. 2020). While a dual approach to addressing moral distress is necessary, institutions have a responsibility to cultivate environments that “support healthy debate and genuine dialogue to ensure high-quality patient care” (Epstein et al. 2020, 147).

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Conflicts of interest. None declared.

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