Palliative and Supportive Care

cambridge.org/pax

Distress, demoralization, and fulfillment among palliative care providers during the COVID-19 pandemic

Michael Tang, M.D.[1], Sujin Ann-Yi, PH.D.[1], Donna S. Zhukovsky, M.D.[1], Bryan Fellman, M.S.[2] and Eduardo Bruera, M.D.[1]

[1]Department of Palliative Care, Rehabilitation and Integrative Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX, USA and [2]Department of Biostatistics, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

Original Article

Cite this article: Tang M, Ann-Yi S, Zhukovsky DS, Fellman B, Bruera E (2024). Distress, demoralization, and fulfillment among palliative care providers during the COVID-19 pandemic. *Palliative and Supportive Care* **22**, 482–486. https://doi.org/10.1017/S1478951523001803

Received: 25 September 2023
Revised: 10 October 2023
Accepted: 05 November 2023

Keywords:
Demoralization; burnout; COVID-19; fulfillment; palliative care

Corresponding author: Michael Tang;
Email: MJTang@mdanderson.org

Abstract

Objectives. Prolonged distress is a risk factor for burnout among health-care providers (HCP) and may contribute to demoralization. We examined sources of distress during the COVID-19 pandemic and associations with demoralization.

Methods. This prospective cross-sectional survey of HCP was conducted among palliative care providers of an academic medical center. Participants completed a survey evaluating sources of distress and the Demoralization Scale-II (DS-II) to measure the intensity of demoralization.

Results. Of 106 eligible participants, 74 (70%) completed the survey. DS-II median (range) score was 2 (0–19). There were no statistically significant associations with demographic characteristics. Participants reported high rates of distress for multiple reasons and high rates of sense of fulfillment (90%) and satisfaction (89%) with their profession.

Significance of results. Our study identified high levels of distress but low demoralization rates. Further study to evaluate fulfillment and satisfaction as protective factors against demoralization and burnout is indicated.

Introduction

As emerging infectious diseases have spread worldwide, their effects on the population are commonly measured by morbidity and mortality; however, the psychological effects on the mental health of the health-care workers (HCW) are often overlooked (Pappa et al. 2020). Several studies have documented depression, anxiety, and posttraumatic stress disorder in HCW after the Middle East respiratory syndrome and severe acute respiratory syndrome (SARS) epidemics (Koh et al. 2005; Lancee et al. 2008; Lee et al. 2018; Tam et al. 2004). For instance, during the 2003 SARS outbreak, HCW expressed significant emotional distress (18% to 57% of HCW) during and after the epidemic (Chan 2004; Maunder et al. 2004; Nickell 2004; Phua et al. 2005).

Psychological impact on HCW is a significant concern during pandemics where health-care providers (HCP) are already often physically overworked or experience prolonged distress (Maslach et al. 2001). Demoralization, defined as a sense of hopelessness and helplessness when purpose and meaning are lost, is an unstudied aspect of mental health that may contribute to burnout in HCW (Agarwal et al. 2020; Robinson et al. 2015). Conceptually, demoralization differs from burnout, in that burnout encompasses a broader definition of depersonalization, reduced feelings of accomplishment and emotional exhaustion (Ishak et al. 2009). Demoralization has been demonstrated in terminal patients and described as a spectrum beginning with disheartenment or mild loss of confidence, leading to despondency, despair, and then full-blown demoralization syndrome (Clarke and Kissane 2002). Demoralization is characterized by diminished morale when one's principles, values, or standards are threatened and have been observed in HCW when facing significant stress that cannot be addressed (Gabel 2013; Jacobsen et al. 2007; Kissane et al. 2004).

The COVID-19 has caused extraordinary and extensive effects on society today (Centers for Disease Control and Prevention 2021). HCW have been on the front lines and have felt burdens that include increased workloads, lack of personal protective equipment, and risk of acquiring the disease, all risk factors for distress, moral injury, and demoralization (Maguen and Price 2020; Pappa et al. 2020). Despite the significant effects that the current pandemic has had on the mental health of HCP, to the best of our knowledge, there have been no studies that have examined the sources of distress, demoralization, and the associated impact on psychological well-being in members of the health-care community. There have been several studies over the years using burnout as a tool to measure psychological distress in the health-care workforce

and in health education (Dahlin and Runeson 2007; Ishak et al. 2009; Rosen et al. 2006; Sharifi et al. 2021). We aim to study demoralization as a novel approach to examine psychological distress in the health-care workforce apart from burnout to better understand its role in mental well-being and how sources of distress affects can affect levels of demoralization in the health-care workforce.

Methods

The institutional review board at MD Anderson Cancer Center in Houston, Texas, approved this prospective cross-sectional survey. The trial took place in the Supportive Care department. Physicians, advanced practice providers, nurses, counselors, and psychologists were considered eligible to participate in the survey. Nurses who do not routinely provide care at the Supportive Care Clinic or the Palliative and Supportive Care Unit, including temporary nurses from other departments or floors, were excluded from this study. Eligible participants were sent an email that included the study's objective, and if willing to participate, a link to obtain informed consent. Consenting participants were then provided a link to the web-based survey.

The survey consisted of a questionnaire composed of 4 subsections formulated by the study investigators (Table 3). The first 3 subsections identified sources of distress in the work and home environments and when caring for patients. The fourth subsection evaluated demoralization. The model used was the Demoralization Scale-II (DS-II) (Robinson et al. 2016). This scale was selected because after extensive literature searches, no published validated tools or measures evaluating demoralization in the study population were identified. DS-II consists of 16 statements, graded based on a numeric rating of 0 for Never, 1 for Sometimes, and 2 for Often (Robinson et al. 2016). Responses are summed to provide the total score out of a maximum possible of 32 points. The total score comprises 2 subscale scores: Meaning and Purpose (MP) and Distress and Coping Ability (DCA), each consisting of 8 questions. This scale has been validated in patients with advanced, progressive disease. Values from 0 to 3, 4 to 10, and 11+ were considered low, middle, and high scorers, respectively (Robinson et al. 2016). Demographic information seen in Table 1 was obtained as part of the survey questions itself.

The study analysis was primarily descriptive. Summary statistics were used to describe the demographic characteristics of our study population as well as all survey items. DS-II total and subscale scores were summarized using means, standard deviations, ranges, and 95% confidence intervals. We compared demographic factors and the DS-II using *t*-test, rank-sum test, ANOVAs, or Kruskal–Wallis test, as appropriate. All statistical analysis was performed using Stata/MP v17.0 (College Station, TX).

Table 1. Participant demographics ($N = 74$)

Characteristic	*N*	%
Age (years)		
20–29	5	7
30–39	19	27
40–49	24	34
50+	22	31
Gender		
Female	56	81
Male	13	19
Role as part of the Supportive Care Department		
Advanced practice provider	23	32
Psychologist/Counselor	5	7
Nurse	20	28
Physician	23	32
Years practicing in the field of supportive and palliative medicine		
0–3	21	30
4–7	17	24
7–11	15	21
11+	17	24
Practiced in a different specialty prior to joining the Supportive Care Department		
Yes	49	69

Table 2. Demoralization scale and subscales

Characteristic	
Demoralization Scale-II Sum ($N = 70$)	
Mean (SD)	3.80 (4.74)
Median (Min–Max)	2 (0–19)
Meaning and Purpose Subscale ($N = 74$)	
Mean (SD)	1.16 (2.07)
Median (Min–Max)	0 (0–10)
Distress and Coping Ability Subscale ($N = 74$)	
Mean (SD)	2.43 (2.90)
Median (Min–Max)	1 (0–11)

Results

This study was conducted from May to July 2022. In total, 106 eligible participants were sent invitations; 74 (70%) participants completed the survey. Table 1 provides a summary of participant demographics. Most were women (81%). A majority (69%) also had practiced in a different specialty before joining the Supportive Care Department.

Table 2 summarizes the results of the DS-II. Of the total respondents, 42 (56.8%) were categorized as low scorers, 20 (27%) as middle scorers, and 8 (10.8%) as high scorers (4 participants had missing values). The median (range) score was 2 (0–19). The 2 subscales, MP and DCA, had median (range) values of 0 (0–10) and 1 (0–11), respectively. There were no statistically significant associations found when assessing demoralization and age, gender, role (physician, counselor/psychologist, nurse, advanced practice practitioner), and practice in a different specialty prior to joining supportive care. A statistically significant difference was found between the DCA subscale score practice in a different specialty prior to supportive care. Those who had practiced in a different specialty had a median (range) score of 3 (0–11) compared to those who had not – 1 (0–9), $p = 0.035$.

Table 3 shows study questions formulated by the investigators to identify sources of distress including increased emotional distress directed at our team from patients and families and other HCP,

https://doi.org/10.1017/S1478951523001803 Published online by Cambridge University Press

Table 3. Survey responses ($N = 74$)

Characteristic	N	%
Patient care		
Extreme distress		
The limited number of family members being able to be physically present at end of life for patients.	53	75
Families only being able to see patients by video technology.	43	61
Limited amount of family members being allowed to be with patients	39	55
Contact with patients who may have COVID-19	35	50
Concerns about transmitting COVID-19 to patients or family members who are allowed in the hospital.	21	29
Completely agree/Somewhat agree		
Patients are in more emotional distress, as compared to before the pandemic.	60	87
Family members are in more emotional distress, as compared to before the pandemic.	60	87
More episodes of emotional distress directed at me from the family members of the patients.	55	79
More episodes of emotional distress directed at me from patients.	52	74
Providing medical information to families/loved ones is difficult due to inability to be at bedside	52	74
Referring clinicians are in more emotional distress, as compared to before the pandemic.	48	70
Providing an accurate prognosis to patients and families difficult, due to lack of face-to-face contact.	39	55
More episodes of emotional distress directed at me from the referring teams.	35	50
Home life		
Completely agree/Somewhat agree		
Concerns about transmitting or contracting COVID-19 from a family member is causing significant distress	40	56
Providing childcare at home is causing significant distress	24	34
Providing care to a family member other than a child at home is causing significant distress.	16	23
Work environment		
Completely agree/Somewhat agree		
Lack of testing for COVID-19 for health-care providers, patients, and family members who are allowed in the hospital is distressing.	29	41
Concerns about being redeployed to another department	28	39
Lack of personal protective equipment in the hospital is distressing.	25	35
Working in close proximity with others causes distress due to concerns of COVID-19 transmission	21	30
Telemedicine to provide care with the patient and family, rather than seeing the patient or family face-to-face is distressing	27	30
Sense of fulfillment and satisfaction with profession		
I have a sense of fulfillment with what I do.	64	90
I have an overall sense of satisfaction with what I do.	62	89
Survey questions and relationship to COVID-19		
Completely agree/Somewhat agree		
The answer choices above are directly related to the COVID-19 pandemic.	31	45

strict visitation policies, and other factors. Participants had a sense of fulfillment in their profession (90%) and a sense of satisfaction in what they did (89%). There were several sources of distress in patient care identified, which included the following: more significant emotional distress from patients (87%), family members (87%), and referring clinicians (70%) now as compared to prior to the pandemic, along with visitation limitations during the pandemic (75%). Participants felt that more episodes of distress were directed at them by patients (74%) and family members (79%).

Discussion

Demoralization has rarely been studied in HCW during COVID-19 (Agarwal et al. 2020; Robinson et al. 2015). When assessing levels of demoralization among supportive care providers during the COVID-19 pandemic, the majority of our participants scored in the lowest interquartile range. They also scored in the lowest interquartile range when evaluating the MP and DCA subscales.

Paradoxically, despite low levels of demoralization, our study identified several significant sources of distress (Table 3). Importantly, when asked whether they had a sense of fulfillment and overall satisfaction with what they did, responses were overwhelmingly positive at 90% and 89%, respectively. Thus, 1 possible explanation for the overall low demoralization scores is that the sense of fulfillment and satisfaction were protective factors against the sense of hopelessness and helplessness (Agarwal et al. 2020; Robinson et al. 2015). This conclusion is supported by a study in Turkey that investigated the psychological resilience of HCW during the COVID-19 pandemic. The authors concluded that life satisfaction was a key factor in improving resilience (Bozdağ & Ergün, 2021). The authors also concluded that risk factors for lower psychological resilience included busy work schedules and exposures to unfavorable events, including deaths. In an Italian study of home palliative care providers during the pandemic, burnout frequency was lower than pre-pandemic for related reasons (Varani et al. 2021). While participants reported increased levels of psychological morbidity compared to pre-pandemic, they had higher levels of personal accomplishment, which was postulated to have a similar protective effect (Varani et al. 2021).

Self-care practices prioritized in this department may also be a mitigating factor of demoralization despite high levels of distress. These self-care activities include movement, rest, hydration, asking for and offering help, eating light meals during the day, breaks, and debriefing under challenging situations (Bramati et al. 2023). Good sleep, healthy lifestyles, along with social support have been shown in other studies to support resilience during the COVID-19

https://doi.org/10.1017/S1478951523001803 Published online by Cambridge University Press

pandemic (Bozdağ & Ergün, 2021; Petzold et al. 2020). Our study suggests that self-care and mindfulness-based activities may be important to evaluate as factors reducing emotional distress that can lead to demoralization and burnout (Ameli et al. 2020).

There are several limitations of this study. This was a single-center trial, and the sample size was small. A larger sample size may have allowed us to see statistically significant differences among demographic groups. This study was conducted from May to July 2022; while the pandemic was no longer at its height, because our institution has among the highest prevalence of immunocompromised patients in the world, pandemic risks and associated precautions were still at the forefront of workforce practices. Moreover, responses to the questions are subject to recall bias. We used the DS-II, validated initially in a population with advanced illness (Kissane et al. 2004); thus, its utility in our study population has not been studied. Also, there are no currently established cut-off values when using the DS-II. We also did not specifically survey psychological distress or burnout other than using the DS-II. We were trying to minimize respondent burden given the number of questions they were asked to respond to in the questionnaire and the DS-II along with the burden already imposed by working during the pandemic. Thus, we cannot conclude how fulfillment and satisfaction play a role in feelings of emotional distress such as anxiety, depression, or even burnout in HCW.

Demoralization and its role in burnout are essential topics to study, given their far-reaching effects on the personal well-being of HCP. Our study implicates the importance of self-care measures and how fulfillment and satisfaction can protect against demoralization. Few studies assess demoralization and its role in burnout, anxiety, and depression. Along with these associations, the relationship between demoralization and resilience could be another topic of interest for future research.

Acknowledgments. The authors thank Kate Krause, in the Research Medical Library at MD Anderson Cancer Center, for her assistance with the literature review.

Author contributions. Michael Tang and Sujin Ann-Yi contributed equally to the manuscript.

Funding. This research was in part supported by the National Institutes of Health through MD Anderson Cancer Center Support Grant CA016672.

Competing interests. None of the authors have any conflicts of interest or disclosures to report.

References

Agarwal SD, Pabo E, Rozenblum R, *et al.* (2020) Professional dissonance and burnout in primary care: A qualitative study. *JAMA Internal Medicine* **180**(3), 395–401. doi:10.1001/jamainternmed.2019.6326

Ameli R, Sinaii N, West CP, *et al.* (2020) Effect of a brief mindfulness-based program on stress in health care professionals at a US biomedical research hospital: A randomized clinical trial. *JAMA Network Open* **3**(8), e2013424. doi:10.1001/jamanetworkopen.2020.13424

Bozdağ F and Ergün N (2021) Psychological resilience of healthcare professionals during COVID-19 pandemic. *Psychological Reports* **124**(6), 2567–2586. doi:10.1177/0033294120965477

Bramati PS, Swan A, Urbauer DL, *et al.* (2023) Evaluation of a daily nine-item "Handbook for Self-Care at Work" for palliative care clinicians. *Journal of Palliative Medicine* **26**(5), 622–626. doi:10.1089/jpm.2022.0347

Centers for Disease Control and Prevention (2021) COVID data tracker. vol. 2021.

Chan AOM (2004) Psychological impact of the 2003 severe acute respiratory syndrome outbreak on health care workers in a medium size regional general hospital in Singapore. *Occupational Medicine* **54**(3), 190–196. doi:10.1093/occmed/kqh027

Clarke DM and Kissane DW (2002) Demoralization: Its phenomenology and importance. *Australian & New Zealand Journal of Psychiatry* **36**(6), 733–742. doi:10.1046/j.1440-1614.2002.01086.x

Dahlin ME and Runeson B (2007) Burnout and psychiatric morbidity among medical students entering clinical training: A three year prospective questionnaire and interview-based study. *BMC Medical Education* **7**, 6. doi:10.1186/1472-6920-7-6

Gabel S (2013) Demoralization in health professional practice: Development, amelioration, and implications for continuing education. *Journal of Continuing Education in the Health Professions* **33**(2), 118–126. doi:10.1002/chp.21175

Ishak WW, Lederer S, Mandili C, *et al.* (2009) Burnout during residency training: A literature review. *Journal of Graduate Medical Education* **1**(2), 236–242. doi:10.4300/JGME-D-09-00054.1

Jacobsen JC, Maytal G and Stern TA (2007) Demoralization in medical practice. *The Primary Care Companion to the Journal of Clinical Psychiatry* **9**(2), 139–143. doi:10.4088/PCC.v09n0208

Kissane DW, Wein S, Love A, *et al.* (2004) The Demoralization Scale: A report of its development and preliminary validation. *Journal of Palliative Care* **20**(4), 269–276. doi:10.1177/082585970402000402

Koh D, Lim MK, Chia SE, *et al.* (2005) Risk perception and impact of Severe Acute Respiratory Syndrome (SARS) on work and personal lives of healthcare workers in Singapore: What can we learn? *Medical Care* **43**(7), 676–682. doi:10.1097/01.mlr.0000167181.36730.cc

Lancee WJ, Maunder RG and Goldbloom DS (2008) Prevalence of psychiatric disorders among Toronto hospital workers one to two years after the SARS outbreak. *Psychiatric Services* **59**(1), 91–95. doi:10.1176/ps.2008.59.1.91

Lee SM, Kang WS, Cho A-R, *et al.* (2018) Psychological impact of the 2015 MERS outbreak on hospital workers and quarantined hemodialysis patients. *Comprehensive Psychiatry* **87**, 123–127. doi:10.1016/j.comppsych.2018.10.003

Maguen S and Price MA (2020) Moral injury in the wake of coronavirus: Attending to the psychological impact of the pandemic. *Psychological Trauma: Theory, Research, Practice, and Policy* **12**(S1), S131–s132. doi:10.1037/tra0000780

Maslach C, Schaufeli WB and Leiter MP (2001) Job burnout. *Annual Review of Psychology* **52**, 397–422. doi:10.1146/annurev.psych.52.1.397

Maunder RG, Lancee WJ, Rourke S, *et al.* (2004) Factors associated with the psychological impact of severe acute respiratory syndrome on nurses and other hospital workers in Toronto. *Psychosomatic Medicine* **66**(6), 938–942. doi:10.1097/01.psy.0000145673.84698.18

Nickell LA (2004) Psychosocial effects of SARS on hospital staff: Survey of a large tertiary care institution. *Canadian Medical Association Journal* **170**(5), 793–798. doi:10.1503/cmaj.1031077

Pappa S, Ntella V, Giannakas T, *et al.* (2020) Prevalence of depression, anxiety, and insomnia among healthcare workers during the COVID-19 pandemic: A systematic review and meta-analysis. *Brain, Behavior, and Immunity* **88**, 901–907. doi:10.1016/j.bbi.2020.05.026

Petzold MB, Bendau A, Plag J, *et al.* (2020) Risk, resilience, psychological distress, and anxiety at the beginning of the COVID-19 pandemic in Germany. *Brain and Behavior* **10**(9), e01745. doi:10.1002/brb3.1745

Phua DH, Tang HK and Tham KY (2005) Coping responses of emergency physicians and nurses to the 2003 severe acute respiratory syndrome outbreak. *Academic Emergency Medicine* **12**(4), 322–328. doi:10.1197/j.aem.2004.11.015

Robinson S, Kissane DW, Brooker J, *et al.* (2015) A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: A decade of research. *Journal of Pain Symptom Management* **49**(3), 595–610. doi:10.1016/j.jpainsymman.2014.07.008

Robinson S, Kissane DW, Brooker J, *et al.* (2016) Refinement and revalidation of the demoralization scale: The DS-II-external validity. *Cancer* **122**(14), 2260–2267. doi:10.1002/cncr.30012

Rosen IM, Gimotty PA, Shea JA, ***et al.*** (2006) Evolution of sleep quantity, sleep deprivation, mood disturbances, empathy, and burnout among interns. *Academic Medicine* **81**(1), 82–85. doi:10.1097/00001888-200601000-00020

Sharifi M, Asadi-Pooya AA and Mousavi-Roknabadi RS (2021) Burnout among healthcare providers of COVID-19; a systematic review of epidemiology and recommendations. *Archives of Academic Emergency Medicine* **9**(1), e7.doi:10.22037/aaem.v9i1.1004

Tam CWC, Pang EPF, Lam LCW, ***et al.*** (2004) Severe acute respiratory syndrome (SARS) in Hong Kong in 2003: Stress and psychological impact among frontline healthcare workers. *Psychological Medicine* **34**(7), 1197–1204. doi:10.1017/S0033291704002247

Varani S, Ostan R, Franchini L, ***et al.*** (2021) Caring advanced cancer patients at home during COVID-19 outbreak: Burnout and psychological morbidity among palliative care professionals in Italy. *Journal of Pain and Symptom Management* **61**(2), e4–e12. doi:10.1016/j.jpainsymman.2020.11.026