

Redmann Provider moral distress in caring for tracheostomy and ventilator dependent children: A cross-sectional evaluation.

Andrew Redmann J¹, Catherine Hart², Matthew Smith², Carrie Martin², Adrienne Borschuk², DonnaMaria Cortezzo E², and Dan Benscoter²

¹Children’s Minnesota

²Cincinnati Children’s Hospital Medical Center

February 2, 2023

Abstract

Objective: To determine levels of moral distress in a pediatric unit caring for patients with tracheostomy/ventilator dependence. **Hypothesis:** Moral distress will be significant in a dedicated pediatric trach/vent unit. **Methods:** The Moral Distress Survey-Revised (MDS-R) is a 21-question survey measuring moral distress in pediatrics. The MDS-R was anonymously distributed to MD/DOs, advanced practice practitioners (APPs), RNs and RTs in a unit caring for tracheostomy/ventilator dependent patients. Descriptive statistics, bivariate and multivariate analysis were performed. **Results:** Response rate was 48% (61/127). Mean MDS-R score was 83 (range 43-119), which is comparable to reported levels in the pediatric intensive care unit. APPs had the highest median rate of moral distress (112, IQR 72-138), while MD/DOs had the lowest median score (49, IQR 43-77). RNs and RTs had MDS-R scores between these two groups (Medians of 91 and 84 respectively). **Conclusions:** Moral distress levels in a unit caring for long term tracheostomy and ventilator dependent patients are high, comparable to levels in pediatric ICUs. APPs had higher levels of distress compared to other groups. This may be attributable to the constant stressors of being the primary provider for complex patients, especially in a high-volume inpatient setting.

Introduction:

Moral distress is a phenomenon that often occurs in intensive care settings and is defined as “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (1). The concept has been described most comprehensively in the pediatric nursing literature, as initial work suggested nurses experienced high levels of moral distress due to their proximity to patients and the hierarchy of decision-making leading limited control of care decisions (2-6). However, recent data suggests that moral distress also affects physicians and advanced practice providers (APPs) caring for critically ill patients, indicating that it is a broader issue than initially theorized (7-10).

While moral distress in critical care situations has been studied, there is comparably scant information about the degree of moral distress providers experience when caring for patients with chronic diseases requiring long term care. Anecdotally, providers caring for children requiring long term ventilatory support with tracheostomy dependence express some degree of moral distress. It is known that families caring for these children report some degree of distress (11), but little is known about the impact on providers caring for this population. To this end, we surveyed providers in an inpatient unit that specializes in the long-term care of patients with tracheostomy and ventilator dependence to determine the degree to which moral distress exists among these providers.

Methods:

Approval was obtained from Cincinnati Children’s Hospital Medical Center (CCHMC) Institutional Review Board. The Transitional Care Center (TCC) is a 24-bed unit housed within the main CCHMC campus that

cares for medically complex pulmonary patients who do not require Intensive Care Unit (ICU) level care but require ventilatory support through either a tracheostomy or long term non-invasive positive pressure ventilation. The goal of the unit is to prepare children and their families to transition from hospital to home care. The median length of stay in the unit for children with new tracheostomy and ventilator support is 146 days. It is staffed by a pediatric pulmonologist who rotates on service weekly, as well as a consistent team of APPs. Patients in the TCC are also cared for by nursing staff and respiratory therapists with experience in caring for children with chronic ventilatory needs, as well as specialty teams (Physical Medicine & Rehabilitation, Neurology, Gastroenterology, Otolaryngology) as indicated for specific patients.

The revised moral distress scale (MDS-R) is a validated survey to measure moral distress in those caring for pediatric patients (8-9). It includes 21 statements describing situations known to cause moral distress in clinical practice and is scored on a 4-point Likert scale with respect to frequency and intensity (**Appendix 1**). The survey is scored by multiplying frequency and intensity, with each individual statement having a range of scores from 0-16. The sum of all 21 products gives an overall score of 0-336. Three additional questions regarding institutional support for morally distressing situations were also included in the survey (9).

The MDS-R survey was administered to all pediatric pulmonologists who regularly staff the TCC (N=13), all APPs who work in the TCC (N=18), all full-time (0.8 FTE or higher) nurses who primarily work in the TCC (N=66), and all full-time respiratory therapists who have the TCC as their primary unit (N=30). A total of 127 surveys were administered between January 2020 and March 2020. Surveys were given in paper format to all respondents in their individual mailboxes and returned via an anonymous envelope to study staff. Prior to distribution of the survey, providers were made aware they would be receiving this at the monthly TCC meeting, and a reminder message was shared with all providers one month after initial distribution of the survey.

Survey responses were entered into a secure REDcap database for data analysis. Descriptive statistics were calculated including means and standard deviations or medians and interquartile ranges for continuous data, and frequencies and percentages for categorical data. We examined demographics and characteristics of each population under study, examined response rates, and characterized responses in relation to population characteristics using t-tests, Wilcoxon Rank Sum tests, or chi square tests. We excluded questionnaires from the analysis that had more than three missing MDS-R data points. All statistics were two tailed and considered statistically significant if $p < 0.05$. All analyses were conducted using the SAS 9.4 software (SAS Institute, Cary, NC). The primary outcome measure was the MDS-R score for the studied populations.

Results:

A total of 127 surveys were distributed, and 61 complete responses were recorded, for a response rate of 48%. Six responses (4 RT, 2 APP) with more than three missing MDS-R data points were received and not included in analysis. 13/13 pulmonology MD/DOs completed the survey, 16/18 of APPs completed the survey, 15/66 of RNs completed the survey and 17/30 of RTs fully completed the survey. Overall demographics are shown in **Table 1**. The majority of respondents were female (73.3%), younger than 40 (78.3%) and worked in the TCC less than five years (56.67%).

Overall MDS-R scores, Uncertainty scores, and Burnout scores in are shown in **Table 2**. Overall MDS-R scores ranged from 0-204, with a median score of 83 (IQR, 43-119). The mean burnout score was 7.4 (IQR 3-10), and this had a moderate positive correlation ($R=0.58$, $p < 0.01$) with MDS-R scores.

Table 3 shows scores for the various provider groups. As a group, APPs had the highest MDS-R scores, with a median score of 112 (IQR, 72-138), while MD/DOs had the lowest mean MDS-R scores, with a median of 49 (IQR, 43-77). This was a statistically significant difference ($p < 0.01$). RNs had a median MDS-R score of 91 (IQR, 41-123), and RTs had a median MDS-R score of 84 (IQR, 32.5-106). There were no other statistically significant differences by vocation. Females had a higher median MDS-R score compared to males (94 vs 54, $p < 0.01$). There were no significant differences in MDS-R scores when looking at years of practice when controlling for vocation.

Discussion:

This novel study evaluated moral distress among providers caring for long term tracheostomy and ventilator dependent patients in a non-ICU setting. Our results suggest that moral distress scores for providers are similar in an inpatient unit caring for children with tracheostomy and ventilator dependence compared to pediatric and neonatal ICUs (4-6,8-9,12). There are similarities between ICU patients and non-ICU tracheostomy dependent patients that may explain this. For example, it is well known that caring for tracheostomy and ventilator dependent children is expensive for both families and health care systems, have high rates of readmission, are complicated by invasive procedures, can entail discussions around goals of care or complex treatment plans, and navigating the limited resources related to home healthcare (often limiting discharge planning) (13-15). These complexities lead to long hospital stays, and this may exacerbate moral distress in settings not designed for long term acute care. Unlike non-hospital based long term acute care facilities (LTAC), there are limitations to providing long term care in the hospital setting. Often these patients are very medically complex, limiting options that would normally mitigate distress, such as planned outings, group activities, and predictable schedules. In addition, patients with lengthy hospital stays of 1 year or more can disrupt or cause bottlenecks in patient flow, placing chronic systemic pressure on staff with respect to space and bed availability.

One particularly novel finding in our study is the high rate of moral distress experienced by APPs. This is likely attributable to a variety of reasons. First, in the TCC, APPs do not rotate off service as often as physicians (physicians cover between 2-6 weeks a year in the unit). The APP's are also responsible for a larger number of patients in the unit than the RN/RTs, which each APP covering 6-10 patients each shift. APPs thus provide a high degree of continuity for all patients in the TCC, and are subjected to the stressors for every patient in the unit for an extended period of time. This is contrasted to attending physicians, who are subjected to stressors for every patient in the TCC, but who rotate off service on a regular basis. RN/RTs, by contrast, are subjected to stressors for extended periods, but care for a discrete number of patients. While all groups surveyed experience moral distress, our hypothesis is that both the amount of patient exposure and the constancy of this exposure plays a role in the degree of moral distress that is experienced by APPs (5,6, 16). Second, APPs are responsible for much of the day-to-day care of patients with the premise of practice autonomy, however, this impacted by inconsistencies in professional equity from attending physician to attending physician. The tension between a high degree of responsibility accompanied by a lack of, or inconsistency in, professional equity may lead to moral distress and burnout. (16-19).

Understanding moral distress is important due to the significant impact it has on burnout and staff turnover (3,8-9, 20-26). In addition, burnout is associated with poorer quality of care, and significant expenses due to decreased clinical productivity and early retirement (24-26). Anecdotally, this has been seen in the TCC, with low rates of engagement among providers for leadership activity outside of clinical work. Understanding factors that are associated with moral distress is important to provide options to decrease distress. Current strategies recommended by the literature focus on mitigating the intensity of stressors, and include education programs, reflective writing, debriefing meetings, and moral empowerment programs (27-28). While some early results are promising, the evidence is unfortunately mixed on the durability of such interventions, and more research is necessary. Our results suggest that along with decreasing the intensity of stressors, decreasing the time of exposure (rotating off service) to distressing situations and better balancing provider authority and responsibility may also be necessary.

Our study has limitations consistent with any survey research. First, a survey is a single snapshot in time, and recent patient interactions may have influenced providers with salient distressing situations to fill out the survey at a higher rate than those who had lower levels of distress (non-responder bias). Second, this study was carried out before the COVID-19 pandemic, and this may skew results, as recent data suggests that the worldwide pandemic may change the degree of moral distress felt by providers (29). Third, about a year prior to this study, a clinical psychologist (APB) was embedded within the unit to deliver evidence-based psychological interventions to patients and families to promote coping and functioning as well as

to help support staff with feelings of distress. Due to this, our rates of moral distress may be lower than similar units without this support in place. Despite these limitations, our study remains the first quantitative examination of moral distress in a non-ICU caring for long term tracheostomy/ventilator dependent patients.

Conclusion:

Moral distress scores are similar in a non-ICU caring for children with tracheostomy and ventilator dependence compared to published data in pediatric intensive care units and neonatal intensive care units. Advanced practice providers had higher rates of moral distress than physicians. The degree of moral distress may be dependent on distress intensity, the duration of exposure, and inconsistencies in professional equity across medical providers.

References

1. McCarthy J, Monteverde S, “The standard account of moral distress and why we should keep it”. HEC Forum. 2018 Dec;30(4):319-328
2. Crippen D. “Moral distress in medicine: Powerlessness by any other name.” J Crit Care. 2016 Feb;31(1):271-2.
3. Dodek PM, Wong H, Norena M, Ayas N, et al. J Crit Care. 2016 Feb;31(1):178-82.
“Moral distress in intensive care unit professionals is associated with profession, age, and years of experience.”
4. Zomorodi M, Lynn MR. Instrument development measuring critical care nurses’ attitudes and behaviors with end-of-life care. Nurs Res. 2010 Jul-Aug;59(4):234-40.
5. Cavaliere TA, Daly B, Dowling D, Montgomery K. “Moral distress in neonatal intensive care unit RNs.” Adv Neonatal Care. 2010 Jun;10(3):145-156.
6. Prentice T, Janvier A, Gillam L, Davis PG. “Moral distress within neonatal and paediatric intensive care units: a systematic review.” Arch Dis Child 2016 2016;101:701-708
7. Chiu PP, Hilliard RI, Azzie G, Fecteau A. Experience of moral distress among pediatric surgery trainees. J Pediatr Surg. 2008 Jun;43(6):986-93
8. Trotochaud K, Coleman JR, Krawiecki N, McCracken C. “Moral Distress in Pediatric Healthcare Providers.” J Pediatr Nurs. 2015 Nov-Dec;30(6):908-14.
9. Larson CP, Dryden-Palmer KD, Gibbons C, Parshuram CS. “Moral Distress in PICU and Neonatal ICU Practitioners: a Cross Sectional Evaluation”. Pediatr Crit Care Med. 2017 Aug;18(8):e318-e326.
10. Solomon MZ, Sellers DE, Heller KS, Dokken DL, et al. “New and lingering controversies in pediatric end-of-life care.” Pediatrics. 2005 Oct;116(4):872-83.
11. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. “Daily Living with Distress and Enrichment: the Moral Experience of Families with Ventilator-Assisted Children at Home”. Pediatrics. 2006 Jan;117(1):e48-e60.
12. Dodek PM, Cheung EO, Burns KEA, Martin CM, et al. “Moral Distress and Other Wellness Measures in Canadian Critical Care Physicians”. Ann Am Thorac Soc 2021 Aug;18(8):1343-1351.
13. Berry JG, Goodman DM, Coller RJ, Agrawal R, et al. “Association of Home Respiratory Equipment and Supply Use with Health Care Resource Utilization in Children”. J Pediatr. 2019 Apr;207:169-175.
14. Berry JG, Glader L, Stevenson RD, Hasan F, et al. “Associations of Coexisting Conditions with Healthcare Spending for Children with Cerebral Palsy”. J Pediatr. 2018 Sep;200:111-117.
15. Watters K, O’Neill M, Zhu H, Graham RJ et al. “Two-year mortality, complications and healthcare use in children with medicaid following tracheostomy”. Laryngoscope 2016 Nov;126(11):2611-2617

16. Pastores SM, Kvetan V, Coopersmith CM, Famer JC. “Workforce, Workload, and Burnout Among Intensivists and Advanced Practice Providers: A Narrative Review”. *Crit Care Med.* 2019 Apr;47(4):550-557
17. Webb SS, Price SA, Coeling HE. “Valuing authority/responsibility relationships. The essence of professional practice”. *J Nurs Adm.* 1996 Feb;26(2):28-33
18. Ashooh MP, Barnette K, Moran TP, O’Shea J, Lall MD. “Advanced Practice Provider Burnout in a Large Urban Medical Center”. *Adv Emerg Nurs J.* Jul/Sep 2019;41(3):234-243.
19. Klein CJ, Dalstrom M, Lizer S, Cooling M, et al. “Advanced Practice Provider Perspectives on Organizational Strategies for Work Stress Reduction”. *West J Nurs Res.* 2020 Sep;42(9):708-717.
20. Lambden JP, Chamberlin P, Kozlov E, Lief L et al. “Association of Perceived futile or Potentially inappropriate care with burnout and thoughts of quitting among health care providers”. *Am J Hosp Palliat Care.* 2018 Aug 5. [Epub ahead of print]
21. Hally SM, Settle M, Nelson BD. “Relationship Between Moral Distress and Intent to Leave a Position Among Neonatal Intensive Care Nurses”. *Adv Neonatal Care.* 2021 May 27 Online ahead of print.
22. Lu DW, Dresden S, McCloskey C, Branzetti J, et al. “Impact of Burnout on Self-Reported Patient Care Among Emergency Physicians.” *West J Emerg Med.* 2015 Dec;16(7):996-1001.
23. Russell K. “Perceptions of Burnout, Its Prevention, and Its Effect on Patient Care as Described by Oncology Nurses in the Hospital Setting”. *Oncol Nurs Forum.* 2016 Jan;43(1):103-9.
24. Dewa CS, Loong D, Bonato S, Trojanowski L. “The relationship between physician burnout and quality of healthcare in terms of safety and acceptability: a systematic review”. *BMJ Open* 2017 Jun 21;7(6):e015141
25. Dewa CS, Jacobs P, Thanh NX, Loong D. “An estimate of the cost of burnout on early retirement and reduction in clinical hours of practicing physicians in Canada”. *BMC health Serv Res.* 2014 Jun 13;14:254.
25. Mills M, Cortezzo DE. “Moral Distress in the Neonatal Intensive Care Unit: What Is It, Why It Happens, and How We Can Address It.”. *Front Pediatr.* 2020 Sep 10;8:581.
27. Imbulana DI, Davis PG, Prentice TM. “Interventions to reduce moral distress in clinicians working in intensive care: A systematic review.” *Intensive Crit Care Nurs.* 2021 Oct;66:103092. Epub 2021 Jun 17.
28. Davis M, Batcheller J. “Managing Moral Distress in the Workplace: Creating a Resiliency Bundle”. *Nurse Lead.* 2020 Dec;18(6):604-608.
29. Thomas TA, Davis FD, Kumar S, Thammasitboon S, Rushton CH. “COVID-19 and Moral Distress: A Pediatric Critical Care Survey”. *Am J Crit Care* 2021 Aug 19;e1-e19. Online ahead of print.

Hosted file

Table 1.docx available at <https://authorea.com/users/582327/articles/622447-redmann-provider-moral-distress-in-caring-for-tracheostomy-and-ventilator-dependent-children-a-cross-sectional-evaluation>

Hosted file

Table 2.docx available at <https://authorea.com/users/582327/articles/622447-redmann-provider-moral-distress-in-caring-for-tracheostomy-and-ventilator-dependent-children-a-cross-sectional-evaluation>

Hosted file

Table 3.docx available at <https://authorea.com/users/582327/articles/622447-redmann-provider-moral-distress-in-caring-for-tracheostomy-and-ventilator-dependent-children-a-cross-sectional-evaluation>