Staff Perceptions of Dying and Death in a Pediatric Cardiac Intensive Care Unit During COVID-19

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Background Strict visitor restrictions during the COVID-19 pandemic have been associated with staff moral distress in numerous clinical settings, yet little is known about effects on perceptions of pediatric end-of-life care.
Objective To determine the effect of COVID-19 visitor restrictions on perceptions of quality of dying and death.
Methods This was a cross-sectional survey of interdisciplinary staff caring for dying children in a cardiac intensive care unit with flexible visitation allowances compared with published policies reported in the literature at the time.
Results No significant difference in perceptions of quality of dying and death was found between the prepandemic and pandemic periods despite similar clinical care provision. The relatively less stringent allowances at end of life did not adversely affect staff risk for infection.
Conclusions The findings support affording some flexibility to visitation at end-of-life, which may mitigate negative staff perceptions of quality of dying and death. With the profound effects of COVID-19 on end-of-life care provision, these results may have implications for future global challenges. (*American Journal of Critical Care.* Published online February 21, 2023.)

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The COVID-19 pandemic profoundly affected health service delivery, including pragmatic changes to visitation policies instituted to mitigate staff exposure.[1-4] As a result of these restrictions, critically ill patients were separated from their loved ones at end of life (EOL), leading to disrupted bereavement in surviving relatives and immense burdens on health care providers.[1,2,5] In pediatrics, parents are essential members of the care team, yet the effect of visitor restrictions on children's EOL care is poorly understood.[3]

Tools for assessing quality of dying and death (QODD) evaluate perceptions of EOL care and have been validated in adults and pediatric intensive care units (PICUs).[6,7] The PICU-QODD instrument was recently shown to be a reliable and valid clinician measure of QODD in the cardiac intensive care unit (CICU) setting.[8] Such tools offer opportunities to identify strategies to improve EOL experiences for staff, and potentially patients and their families.[9] We conducted a secondary analysis of a pediatric CICU staff survey to determine the effect of COVID-19 visitor restrictions on perceptions of QODD.

No evidence supports restrictive visitation policies, which have been heavily criticized, particularly in pediatrics.

Methods

We performed a single-site cross-sectional survey and medical record review of all deaths at a quaternary pediatric CICU in 2 years (June 30, 2019, to July 1, 2021). The detailed methodology, institutional review board approval, and survey validation were previously published.[8] Interdisciplinary staff including bedside nurses, allied health staff (social workers, child-life specialists, and respiratory therapists), and medical providers (attending physicians, nurse practitioners, and trainees) involved in a decedent's care were invited to complete a survey with consent implied by their voluntary completion. The survey included PICU-QODD questions and 2 additional global items rating quality of the moment of death and quality of life in the 7 days preceding death, with opportunity for free-text responses. The PICU-QODD consists of 20 items evaluating the dying process (including family presence) and death that are scored on a Likert scale (from 0 [terrible] to 10 [ideal]). Standardized overall scores (0-100) were calculated for surveys with at least 80% responses.[7,8] Surveys returned within 14 days of the child's death were included.

Patient-level data included demographics, diagnoses, palliative care involvement, and medical therapies in the 7 days preceding death. Medical intensity was dichotomized as low (not requiring cardiopulmonary resuscitation [CPR] or mechanical support, receiving inotropes without respiratory support, or noninvasive/invasive ventilation with ≤1 inotrope) or high (invasive ventilation with >1 inotrope, open chest, mechanical support, or CPR). Mode of death was defined as follows: maximal resuscitation (CPR), treatment limitation, discontinuation of life-sustaining therapy (DLST), comfort care only (no interventions), and brain death.[10]

To examine the effect of our institutional visitation policy at EOL on staff perceptions of QODD, we divided the original cohort into prepandemic and pandemic epochs.[8] Starting in March 2020, only the same 2 adult CICU visitors were permitted at bedside throughout admission, a change from the prepandemic policy of no limitations. Siblings and other family members were allowed to visit proximate to EOL with unit nursing and physician leadership oversight. Symptomatic staff underwent COVID-19 testing, and sick calls related to COVID-19 were recorded by occupational health and safety (OHS) staff, who investigated cases for on-site exposures to determine nosocomial infection. We obtained aggregate results for CICU staff during the study period from OHS records.

Staff respondent and patient characteristics were compared between epochs by use of Fisher exact or Wilcoxon rank sum tests. To compare survey

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responses, logistic regression with Huber-White estimates of SEs accounted for correlations between multiple surveys per patient. Analyses were performed in Stata version 16. Free-text responses related to COVID-19 were manually searched by using terms related to "virus" and "visitation."

Results

We received 713 completed surveys (n = 455 [64%] in the pandemic epoch), with a 72% response rate for 60 patient deaths (n = 38 [63%] in the pandemic epoch). Staff respondent variables between epochs were not significantly different (see Table). Patient-level and clinical-level variables did not differ significantly between epochs apart from the older age of patients during the pandemic (see Table). Standardized PICU-QODD scores did not differ significantly between epochs (mean difference, 0.9 [95% CI, 3.6, -1.8], $P = .51$). Individual items related to family presence, quality of moment of death, and quality of life in the 7 days preceding death also did not differ significantly between epochs (see Table and Figure, panel A). Results for the PICU-QODD and individual items did not differ significantly between epochs when compared across staff discipline, years of clinical experience, intensity of EOL therapies, or palliative care referral.

Of 312 total free-text responses (n = 97 [31%] prepandemic and n = 215 [69%] pandemic), only 4 (1.9%) specifically related to COVID-19 or visitation restrictions (see Figure, panel B).

There were no documented nosocomial COVID-19 infections in CICU staff (of 258 patient-facing CICU employees) during the study period. The patient infection rate was 0.71%.

Discussion

The pandemic did not negatively influence CICU staff PICU-QODD scores or perceptions of quality of the moment of death, or quality of life in the 7 days preceding death, despite similar clinical care provision. This result is in the context of less stringent restrictions at EOL compared with publications from other institutions.[2,4] We also observed low nosocomial infection rates. Despite the immense impacts of COVID-19 on daily life and health care provision generally, the pandemic and visitation restrictions were explicitly mentioned in less than 2% of free-text responses.

Health care administrators have the unenviable position of balancing pandemic safety precautions with harms of precluding the physical presence of loved ones at EOL.[11] Compared with our pandemic-related institutional policies, significantly stricter visitor restrictions were reported in adult medicine and other pediatric centers.[4] Despite the well-intentioned rationale, no evidence supports that stringent caregiver restriction policies reduce nosocomial spread of COVID-19.[3,12] Adult critical and pediatric palliative care providers have reported moral distress from enforcing restrictive family visitation policies.[4,13] Restrictions to visitation have been heavily criticized, particularly in pediatrics.[3,12] Physical connection between parents and their dying child is a critical component of a "good death" experience.[14,15] To overcome obstacles, pediatric CICU staff, like adult providers, have endeavored to "fill the gap" by using innovative communication methods to connect patients and relatives.[13]

Limitations must be considered when interpreting these results. This study was performed in a single pediatric quaternary center, thus limiting the generalizability of our findings without the ability to make comparisons between different visitation policies. Relative to adult centers, we report overall low patient infection rates, although parents were not routinely tested. Additionally, staff were not directly tested as part of this study. Noninstitutional testing results were voluntarily provided by staff when they notified OHS of their need for absence. This factor may influence inferences relating to absent nosocomial infection with more liberal visitation restrictions. We did not include the perspectives of family members directly affected by visitor restrictions. Our objective was to study the clinicians' perspective, which is justified for several reasons.[4,7,8,16] Interdisciplinary staff in the CICU play an integral role in supporting children and families at EOL. Moral distress surrounding EOL care is a key driver of poor staff health, and this distress was heightened during the pandemic.[5] Enhancing the experience of staff caring for patients at EOL may promote staff well-being, a core priority in contemporary health care. Because clinicians are often involved in multiple pediatric deaths during their career, they can provide comparative reference frames. Finally, the absence of robust, validated clinical pediatric EOL care quality indicators combined with challenges ascertaining perspectives of newly bereaved family members make staff perceptions a valuable way of measuring the quality of provision of EOL care.[16,17]

The pandemic did not negatively influence CICU staff perceptions of QODD, quality of the moment of death, or the 7 days preceding death.

Conclusion

Our data support that staff perceptions of QODD were not adversely affected by the visitor restrictions

Table
Respondent, patient data, and survey responses compared from before to during the COVID-19 pandemic

Respondent-level variable	Prepandemic, No. (%) n=258 (36%)	Pandemic, No. (%) n=455 (64%)	*P*
Surveys distributed (response rate)	370 (70)	624 (73)	—
Responses with PICU-QODD scores	231 (90)	406 (89)	—
Discipline[a]			.87
Medical provider	78 (30)	130 (28)	
CICU attending	25 (10)	46 (10)	
Nurse practitioner	19 (7)	45 (10)	
CICU fellow	28 (11)	33 (7)	
Cardiac surgeon	1 (<1)	3 (1)	
Cardiology attending	1 (<1)	2 (<1)	
Other ICU attending	4 (2)	1 (<1)	
Registered nurse	89 (35)	157 (35)	
Allied health staff	91 (35)	168 (37)	
Respiratory therapist	48 (19)	90 (20)	
Child life specialist	12 (5)	38 (8)	
Social work	13 (5)	19 (4)	
Chaplain	5 (2)	13 (3)	
Palliative care team	3 (1)	1 (<1)	
Staff years of clinical experience			.28
<2	47 (18)	65 (14)	
2-<5	67 (26)	119 (26)	
5-<10	56 (22)	89 (20)	
10-15	35 (14)	60 (13)	
>15	52 (20)	122 (27)	
Patient-level variable[b]	**Prepandemic, No. (%) n=22 (37%)**	**Pandemic, No. (%) n=38 (63%)**	***P***
Age, median (IQR), d	38 (9-262)	209 (36-8 yr)	.047
Medical admitting team (vs surgical)	11 (50)	20 (53)	.99
Mode of death			.91
Discontinuation of therapy	14 (64)	25 (66)	
Limitation to therapy	3 (14)	7 (18)	
Cardiopulmonary resuscitation	4 (18)	4 (11)	
Comfort care only	1 (5)	1 (3)	
Brain death	0 (0)	1 (3)	
Therapies[c]			
Invasive procedure(s)	9 (41)	16 (42)	>.99
Mechanical support[c]	9 (41)	18 (47)	.79
Open chest	6 (27)	10 (26)	>.99
Awareness (never/rarely)	14 (64)	29 (76)	.38
Mobility (bedbound[d])	14 (64)	27 (71)	.58
Chest compressions	6 (27)	8 (21)	.75
Medical intensity[e]			.79
Low	9 (41)	18 (47)	
High	13 (59)	20 (53)	
Palliative care involvement (vs no/unknown)	11 (50)	21 (55)	.78
Survey response,[f] median (IQR)	**Prepandemic**	**During pandemic**	***P***
Standardized PICU-QODD score	91.9 (82.6-96.9)	92.7 (86.1-97.0)	.51
Quality of life in last 7 days	5 (2-7)	5 (2-7)	.92
Quality of the moment of death	8 (7-10)	9 (7-10)	.65
Family presence	10 (9-10)	10 (10-10)	.32

Abbreviations: CICU, cardiac intensive care unit; ICU, intensive care unit; PICU-QODD, Pediatric Intensive Care Unit Quality of Dying and Death instrument.

[a] Staff involved in more than one patient death could respond multiple times. Nurse practitioner includes 2 consult nurse practitioners. Other includes nutrition interpreter/music therapist/resource specialist. Other includes 8 (3%) prepandemic and 3 (1%) during the pandemic. Not recorded includes 2 (1%) prepandemic and 4 (1%) during the pandemic.

[b] No COVID-19–related deaths.

[c] Therapies used in the week before death; mechanical support includes extracorporeal membrane oxygenation (ECMO) or ventricular assist devices.

[d] Versus patients who were able to be maintained in a chair or be held.

[e] Low intensity: no therapies, inotropic agents without respiratory support, and noninvasive or invasive ventilation with or without 1 inotropic agent. High intensity: invasive ventilation with >1 inotropic agent, having an open chest, receiving ECMO, or cardiopulmonary resuscitation.

[f] Total number of responses for prepandemic and during the pandemic, respectively: overall, N=258 (36%) and 455 (64%); standardized PICU-QODD score, n=231 and 406; quality of life in last 7 days, n=238 and 418; quality of the moment of death, n=111 and 170; family presence, n=250 and 440.

due to the pandemic, although we note that our study institution had more lenient policies than other institutions. Affording some flexibility to visitation at EOL may mitigate the staff distress caused by the absence of the family at the bedside and did not result in elevated staff infection risk. These results may have implications for developing visitation policies in future global health challenges that require balancing infection risk with the distress associated with restrictive visitation policies.

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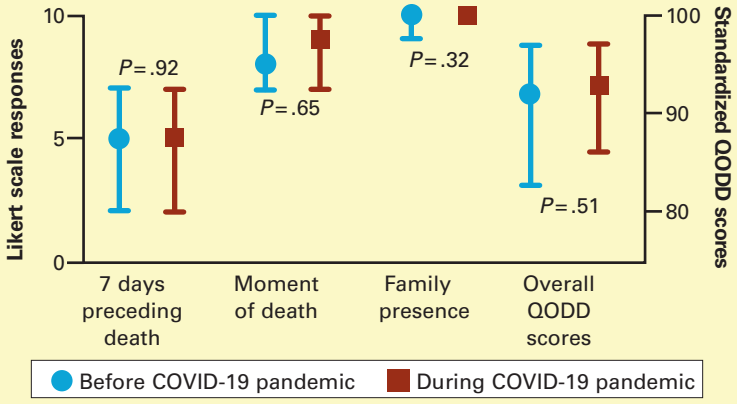

B

"COVID prevented all desired visitors from coming, which was hard for the family. We had Zoom set up for them, however. She had very symptomatic heart failure and the last few days were quite hard for her with dyspnea."

"COVID made calling family in difficult."

"I know special accommodations were made so family (grandparents and siblings) could visit before her passing."

"Struggle with management to let extended family members in"

Figure A, Comparison of prepandemic and pandemic responses to individual items (quality of life in the 7 days preceding death, quality of the moment of death, and family presence [Likert scale: 0, terrible, to 10, ideal, left axis]) as well as standardized scores on the Pediatric Intensive Care Unit Quality of Dying and Death (PICU-QODD) instrument (0-100, right axis). Symbols indicate medians, and whiskers indicate interquartile ranges. B, Free-text responses related to COVID-19 or the visitation policy.

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