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What Does the Staff Think?: Factors Associated With Clinical Staff Perceptions of What Constitutes High-Quality Dying and Death at a Tertiary Pediatric Hospital

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Introduction

It is estimated that approximately 58% of all pediatric deaths¹ take place in an inpatient medical facility. Facilitating a comfortable death in dying pediatric patients is worthy goal for all pediatric care team members. Current evidence suggests that many children suffer in their last days.²⁻⁷ Improving the quality of dying and death requires an understanding of the myriad factors that contribute to a high quality dying and death experience. Even in the same institution, this experience may vary due to differing patient populations and staff culture. Instruments to measure end of life care (EOL) quality have been developed for adult patients. There are few pediatric tools to measure quality of dying and death.⁸⁻¹⁰

There are approximately 100 pediatric deaths per year at this 520 bed pediatric tertiary care hospital in California. In an effort to understand the experience of dying in a pediatric hospital and identify areas for possible improvement, a study was undertaken to evaluate the dying and death experience by obtaining the perspectives of clinical staff that cared for children in the final 3 days of their lives utilizing a unique electronic survey. The survey was administered to a convenience sample of hospital clinical staff that cared for a child in the final 3 days of their life.

Methods

This is a descriptive retrospective analysis of a convenience sample of hospital clinical staff that cared for dying children in a tertiary care setting utilizing a unique electronic survey. Approval for the study with a waiver for written informed consent was obtained from the participating hospital's institutional review board. Hospital units who participated were Medical/surgical, emergency department, oncology, neonatal, pediatric and cardiac care intensive care units and a sub-acute pediatric facility on the main campus. Over a one year period, surveys were sent out electronically to all clinical staff on units where a death

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occurred. The survey instructions asked all clinical staff who cared for a patient in the final 3 days of their life to fill out a 48 question electronic survey. Registered nurses, Nurse Practitioners, respiratory therapists, physicians, child life specialists, social workers, and hospital-based chaplains were included as clinical staff. There were 309 surveys were returned during the 1 year study period and there were 90 deaths during that same period. (Table 1).

The study utilized a unique electronic survey designed to identify factors associated with staff's perception of high quality dying and death. The survey was designed to address each of the domains of dying and death care identified by the National Consensus Project for Quality of Palliative Care. In this theoretical model, 8 domains of dying and death care are identified as: physical aspects, structure and process, psychological and psychiatric aspects, social aspect, spiritual, religious and existential, cultural, ethical and legal aspects, and care of the patient at the end of life.¹¹

The survey mirrored, as much as possible, components of the Quality of dying and death (QODD) instrument. At the time this study had been conducted there were no reports that this instrument had been validated for pediatric populations.¹⁰ The survey mirrored, as much as possible, components of the Quality of dying and death (QODD) instrument.¹²⁻¹³ The QODD instrument was modified to be used in the pediatric population by internal and external experts who included palliative care nurses, physicians, chaplains and social workers thus attaining face validity. The survey included a 5- subscale tool for questions regarding perceptions of quality and a yes/no format for the presence or absence of various components of care. The key question in the study was "Overall, how would you rate the quality of the patient's dying?" Possible responses were: worse possible, poor, neutral (neither bad or good), good, best possible. Qualitative data was solicited with open text options for many of the questions.

Results

This was a descriptive retrospective analysis of a convenience sample of hospital clinical staff that cared for dying children in a tertiary care setting utilizing a unique electronic survey. In the analysis, quality reports are converted from a 5-item ordinal scale to numerical scale (ranging from 1 to 5). Similarly, reports of pain, anxiety or agitation, and difficulty breathing are converted from a 5 point ordinal scale (never, a little bit of the time, some of the time, a good bit of the time, most of the time, all of time) to a numerical scale (ranging from 0 to 5). Statistical analysis assessed the impact of variables of interest on reported quality with the Mann-Whitney U test, Kruskal Wallis test, or linear regression where appropriate. All analyses were conducted with the R statistical programming language.

There were 90 deaths over the one year survey period and there were 309 surveys returned by staff. The percentage of surveys returned by each unit mirrored closely the percentage of institutional deaths during the study year. The highest number of deaths that year, approximately 79%, took place in the Intensive Care units. In the free text sections of many of the questions, clinical staff shared detailed and compelling stories about the experience of caring for a dying child. (Table 5) Out of 309 individual responders, 187 individual

qualitative responses were recorded and were analyzed separately and are reported elsewhere.¹⁴

Physical Domain

Overall, 8.8% of death experiences were rated “worse possible” or “poor” by staff. In the physical domain of the dying process, there were improved quality ratings by clinicians when the hospitalized pediatric patients had less physical symptoms of pain, difficulty breathing, or anxiety. (Table 2)

Structural and Process Domain

In the structural and process domain, perceived quality of the dying and death experience varied between departments with highest ratings on the hematology and oncology unit. A high quality rated multi-disciplinary team, a chaplaincy consult, and a consult to the pain service were correlated with high quality death experience. (Tables 3,4)

Structure and Process Domain

Structure and Process aspects which contributed to the perception of high quality EOL experience were having appropriate orders specific to easing EOL symptoms like pain or dyspnea. Also clarifying the goals of care with a documented do-not resuscitate (DNR) status contributed to perceptions of high quality. (Tables 3,4) Males and clinicians with a higher level of formal education rated the quality higher. Depending on the role of the clinician, there was variability in the perceived quality of the event. Chaplains rated the EOL quality higher than other clinicians; bedside nurses rated the quality the lowest. (Table 1)

Lack of training in end of life (EOL) issues was a factor in lower quality ratings of the death experience. Thirty three percent of the staff caring for a child in the final 3 days of their life had no hours of training in end of life care and 25.6% of the staff had less than 6 hours of training. (Table 4)

Psychological and Psychiatric Domain

In the psychological and psychiatric domain, highest quality was found in situations where the clinician’s needs were met, there were no unresolved needs, the clinician felt no distress from family conflict, the patient and family received psychological care, and there were no formal debriefing (perhaps representing a less complex death). (Table 3)

In this sample, 20.9% of the responders to the survey reported that they had unresolved feelings or stress from the event and this factor was associated with a perceived low quality death experience. Staff distress from family conflict was reported 62.0% of the time and this was also associated with lower reported quality. Having support from staff was associated with higher quality. Staff also reported other sources of distress such as moral or ethical issues (17.7%), other care team members (20%), plan of care for the patient (14.7%) and legal issues (4.4%). Caregiver distress was also an ongoing theme in the free text responses by the staff. (Tables 3,5)

Social, Spiritual, Religious, Existential, and Cultural Domains

In the social domain, highest quality was noted when the patient was thought to be well supported by family and friends. In the spiritual, religious and existential domain, the EOL experiences were rated as of higher quality when the patient and family had spiritual support. (Table 3)

Higher quality ratings for the dying and death experience in the cultural domain were associated with the clinician feeling that the family and/or patient had their cultural needs met. (Table 3)

Ethical and Legal Aspects Domain

For the domain of ethical and legal aspects, there was a negative correlation with quality when the clinician reported any ethical or legal issues such as conflict between goals of care or treatment. (Table 3)

Care of the Patient at the EOL Domain

In the care of the patient at the EOL domain, deterioration necessitating transfer to a higher level of care and unexpected death were negatively correlated with a high quality EOL experience. Higher quality was perceived when the patient was not alone at time of death, there was an opportunity for memory making (such as hand prints), the clinician felt the patient was at peace, the patients and families wishes were honored and they had discussed their EOL goals. The survey asked the respondents to identify if the patient died on their shift or within 3 days of their shift and higher quality was noted if the patient died on the reporting staff's shift. (Tables 3, 4)

Discussion

The death of a child is the most tragic of human experiences. This study highlighted that, for the clinical staff, all deaths were not of equal quality: for the reported deaths in this study 8.8% of death experiences were rated as either "worse possible" or "poor". Even though the staff reported a relatively small number of negative death experiences, the impact on the parents and staff may be far reaching. For parents, serious long term physical and mental morbidity have been reported in the literature.¹⁵⁻¹⁸ For staff, when the death was perceived as low quality, 20% of the responders to the survey reported that they had unresolved feelings or stress from the event. This finding is consistent with research on caregiver distress with end of life care and the serious long term outcomes for the caregiver such as burn out, depression and compassion fatigue.¹⁹⁻²² The ripple effect from the death of a child makes it even more imperative that the care delivered by health care institutions be of the highest quality.

A review of the findings associated with the perception of low quality suggested that the structure and process domain of the EOL experience contributed to the results. The most obvious deficit was the lack of training in EOL care: 33% of the staff of the staff caring for a child in the final 3 days of their life reported that they had no hours of training in end of life care and 24% of the staff had less than 6 hours of training. Lack of consistent and universal

training in EOL care has been identified as a major challenge to improving the quality of care delivered by our health care system.²³⁻²⁶

When a patient was perceived by staff to physically suffer, they rated the quality of the EOL experience lower. This is consistent with findings in pediatric literature that support the fact that pain, agitation/anxiety, and dyspnea at the end of life are common and disturbing to staff and families.²⁻⁷ Having appropriate care orders specifically to alleviate EOL symptoms and clarifying the goals of care contributed to perceptions of high quality. Overall, this study highlighted that established policies and procedures alleviate suffering and contributed to a higher perceived quality death for pediatric patients.

Deterioration and unexpected death are traumatic events for parents, families, and staff and had a negative impact on the quality of the death experience. Of course, every effort is made to prevent a preventable death. In recent years, systematic approaches to identifying potential clinical deterioration have been developed. Increasingly popular are rapid response teams and tools to quantify signs or symptoms associated with sudden deterioration. In the institution that was studied, a rapid response team was utilized and the pediatric early warning system was being piloted during the study period on unit which had the highest rated quality dying and death. Soon after the study closed, it was expanded throughout the inpatient facility. Over time with this quality intervention perhaps the lower quality scores for patients transferred emergently to the PICU or dying unexpectedly may be improved.²⁷⁻²⁸

This report highlights that there was variability both in the quality of dying and death between patients and in the perceived quality of dying and death throughout the units of the hospital. The hematology/oncology unit was reported by participants as having the highest perceived quality dying and death for their patients. This may reflect the differences in resources that were available on the different units in that institution or the different population served. The Hematology/Oncology unit had a very robust and established program for EOL care. On this unit, there are higher rates of EOL training for the staff, high utilization of pain and chaplaincy services, an experienced and well-staffed child life team, a higher percentage of social work coverage than other units, patient and family liaisons who provide culturally sensitive support to families and patients. There also is a high utilization of an EOL order set which standardizes available symptom management options, a supportive care coordinator nurse who is assigned to high risk patients and guides staff and families through the EOL journey including goals of care discussions, a full time psychologist, and integrative care services such as healing touch and acupuncture available on site. Interestingly enough, in a study at the same institution, the same unit reported lowest nursing staff burnout and highest job satisfaction.²²

One of the strengths of this study was the use of an electronic survey format. This provided the staff opportunity to record their thoughts of recent cases soon after the experience. Survey solicitations were sent out within 24 hours of a death to the unit or units where the child was cared for in the final 3 days. There are several limitations to this study. First, because there is no gold standard for measuring the quality of dying and death in pediatrics, therefore we were only able to evaluate associations between various hypothetical constructs

and individuals perception of quality. Second, although we assessed the quality of dying and death from the perspectives of any clinical staff person involved in the care of a dying pediatric patient, we did not assess the perspective of parents and family. Thirdly, this study was conducted on only one hospital and may not be generalized to other hospitals or geographical locations.

Going forward, a closer examination of the EOL care of the units which were rated as delivering the highest quality EOL care is warranted. With a greater understanding of the systems and practices in place on those higher quality units, targeted improvement efforts could then be made in other units to provide a uniform standard of care throughout and improve this institution's overall quality of EOL care. Efforts to provide the staff with EOL education and psychological support could decrease lingering distress and improve quality. Earlier identification of clinical deterioration, goals of care discussions, and plan of care need to be made to assure that EOL care to children and families is of the highest possible experience. Further research into quality of dying and death in pediatrics is needed. Additionally validated instruments that measure perceptions of end of life experiences for pediatrics in various setting would provide a measure to evaluate end of life programs in a variety of settings.

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References

1. Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2013 on CDC WONDER Online Database, released 2015. Data are from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/ucd-icd10.html> on Aug 31, 2015 3:12:27 PM
2. Hechler T, Blankenburg M, Friedrichsdorf SJ, et al. Parent's perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klin Padiatric*. 2008; 220:166–174.
3. Kuhlen M, Hoell J, Balzer S, Borkhardt A, Janssen G. Symptoms and management of pediatric patients with incurable brain tumors in palliative home care. *Eur J Paediatr Neurol*. 2016; 20(2): 261–9. [PubMed: 26753538]
4. Zimmermann K, Bergstraesser E, Engberg S, et al. When parents face the death of their child: a nationwide cross-sectional survey of parental perspectives on their child's end-of life care. *BMC Palliat Care*. 2016; 15:30.doi: 10.1186/s12904-016-0098-3 [PubMed: 26956995]
5. Blume ED, Balkin EM, Aiyagari R, et al. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study. *Pediatr Crit Care Med*. 2014; 15(4):336–42. [PubMed: 24583501]
6. Vollenbroich R, Borasio GD, Duroux A, Grasser M, Brandstätter M, Führer M. Listening to parents: The role of symptom perception in pediatric palliative home care. *Palliat Support Care*. 2016; 14(1): 13–9. [PubMed: 25998176]
7. Gilmer MJ, Foster TL, Bell CJ, Mulder J, Carter BS. Parental perceptions of care of children at end of life. *Am J Hosp Palliat Care*. 2012; 30:53–58. [PubMed: 22495794]

8. Hales S, Zimmermann C, Rodin G. Review: The quality of dying and death: a systematic review of measures. *Palliat Med.* 2010; 24:127–144. [PubMed: 20085963]
9. Lendon JP, Ahluwalia SC, Walling AM, et al. Measuring experience with end-of-life care: A systematic literature review. *J Pain Symptom Manage.* 2015; 49:904–915. [PubMed: 25543110]
10. Sellers DE, Dawson R, Cohen-Bearak A, Solomond MZ, Truog RD. Measuring the quality of dying and death in the pediatric intensive care setting: The clinician PICU-QODD. *J Pain Symptom Manage.* 2015; 49:66–78. [PubMed: 24878067]
11. [August 10, 2015] The National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care. 32013. Available from: http://www.nationalconsensusproject.org/Guidelines_Download2.aspx
12. Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR. Factors associated with nurse assessment of the quality of dying and death in the intensive care unit. *Crit Care Med.* 2004; 32:1648–1653. [PubMed: 15286539]
13. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The quality of dying and death questionnaire (QODD): Empirical domains and theoretical perspectives. *J Pain Symptom Manage.* 2010; 39:9–22. [PubMed: 19782530]
14. Spalding, CN. A phenomenologic study of health professionals' perceptions of good and bad hospital deaths, self-care needs, and lingering distress. Available from ProQuest Dissertations & Theses A&I. 2015. (3713782). (1698463134) Available from: <http://search.proquest.com/docview/1698463134?accountid=14524>
15. Lannen PK, Wolfe J, Prigerson HG, Onelov E, Kreicbergs UC. Unresolved grief in a national sample of bereaved parents: Impaired mental and physical health 4 to 9 years later. *J Clinical Oncol.* 2008; 26(36):5870–5876. [PubMed: 19029425]
16. Boyden JY, Kavanaugh K, Issel LM, Eldeirawi K, Meert KL. Experiences of African American parents following perinatal or pediatric death: a literature review. *Death Stud.* 2014; 38:374–380. [PubMed: 24666143]
17. Van der Geest IM, Darlington AS, Streng IC, Michiels EM, Pieters R, Vrbennettan den Heuvel-Eibrink MM. Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *J Pain Symptom Manage.* 2014; 47(6):1043–53. [PubMed: 24120185]
18. Snaman JM, Kaye EC, Torres C, Gibson D, Baker JN. Parental Grief Following the Death of a Child from Cancer: The Ongoing Odyssey. *Pediatr Blood Cancer.* 2016 May 17.doi: 10.1002/pbc.26046
19. Trotochaud K, Coleman JR, Krawiecki N, McCracken C. Moral distress in pediatric healthcare providers. *J Pediatr Nurs.* 2015; 30:908–914. [PubMed: 25869472]
20. Brandon D, Ryan D, Sloane R, Docherty SL. Impact of a pediatric quality of life program on providers' moral distress. *MCN Am J Matern Child Nurs.* 2014; 39:189–197. [PubMed: 24759312]
21. Branch C, Klinkenberg D. Compassion fatigue among pediatric healthcare providers. *Am J Matern Child Nurs.* 2015; 40:160–166.
22. Sekol MA, Kim SC. Job satisfaction, burnout and stress among pediatric nurses in various specialty units at an acute care hospital. *J Nurs Educ and Pract.* 2014; 4:115–124.
23. Goggin J, Cohen RI. CF healthcare workers feel unprepared in providing suitable end of life care and desire more education: Results of a nationwide survey. *J Cyst Fibros.* 2016; 15(1):85–9. [PubMed: 26362397]
24. McConnell T, Scott D, Porter S. Healthcare staff 's experience in providing end-of-life care to children. A mixed-method review *Palliat Med.* 2016 Apr 29.
25. Arzuaga BH, Caldarelli L. Paediatric trainees and end-of-life care: A needs assessment for a formal educational intervention. *Perspect Med Educ.* 2015; 4:25–32. [PubMed: 25645998]
26. Litauska, Marszalek A., Kozikowski, A., Nouryan, CN., Kline, M., Pekmezaris, R., Wolf-Klein, G. Do residents need end-of-life care training? *Palliative and Supportive Care.* 2014; 12:195–201. [PubMed: 23672997]
27. Murray JS, Williams LA, Pignataro S, Volpe D. An integrative review of pediatric early warning system scores. *Pediatr Nurs.* 2015; 41:165–174. [PubMed: 26470465]

28. Bonafide CP, Localio AR, Roberts KE, Nadkarni VM, Weirich CM, Keren R. Impact of rapid response system implementation on critical deterioration events in children. *JAMA Pediatr.* 2014; 168:25–33. [PubMed: 24217295]

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Table 1

Clinician location and role. Significance is determined by the Kruskal-Wallis test for location and role.

Location	N	Mean (SD) of quality rating by staff best possible 5 to 1 worse possible)	p-value
Heme / Onc	43 (14.2%)	4.38 (0.79)	0.019 *
PICU	121 (39.9%)	4.19 (1.00)	
NICU	76 (25.1%)	4.02 (1.07)	
CVICU	24 (7.9%)	4.00 (1.26)	
Medical / 4E	14 (4.6%)	3.93 (0.83)	
Sub-Acute pediatric facility	10 (3.3%)	3.89 (1.27)	
ED	15 (5.0%)	3.00 (1.41)	
Clinician Role	N	Mean (SD)	p-value
Pastor	40 (13.0%)	4.74 (0.82)	<0.001 ***
Social Worker	27 (8.8%)	4.36 (0.86)	
Supportive Care Team Member	5 (1.6%)	4.20 (0.84)	
MD	23 (7.5%)	4.14 (0.73)	
Other	29 (9.4%)	4.12 (1.20)	
NP	10 (3.3%)	3.80 (1.32)	
Bedside RT	27 (8.8%)	3.76 (1.23)	
Childlife	9 (2.9%)	3.75 (0.71)	
Bedside RN	137 (44.6%)	3.67 (1.11)	

Significance Codes:

*
<0.05,

**
<0.01,

<0.001

Table 2

Physical and structure/process domains. Linear regression results for the perception of the quality of death (5 best possible to 1 worse possible) by pain, difficulty breathing, and anxiety or agitation.

Covariate	Beta	Std. Err.	p-value
(Intercept)	4.274	0.072	
Pain	-0.324	0.062	<0.001 ***
(Intercept)	4.274	0.072	
Difficulty Breathing	-0.111	0.041	0.007 **
(Intercept)	4.224	0.073	
Anxiety / Agitation	-0.255	0.064	<0.001 ***

Significance Codes:

*
<0.05,

**
<0.01,

<0.001

Table 3

Factors associated with significant differences in reported quality by clinical staff. A score of 5 is “best possible”, a score of 1 is worse possible. Data is presented as mean of quality rating (standard deviation); sample size (percentage). Significance is determined by the Mann-Whitney U test. A score of 5 is “best possible”, a score of 1 is worse possible.

Survey Questions	No	Yes	p-value
Structure/process domains			
EOL Order Set in place?	3.85 (1.14); 196 (69.5%)	4.56 (0.70); 86 (30.5%)	<0.001***
DNR/AND Order on chart?	3.68 (1.21); 137 (48.6%)	4.43 (0.78); 145 (51.4%)	<0.001***
Were there adequate orders to alleviate EOL suffering?	2.54 (1.05); 13 (8.3%)	4.30 (0.81); 143 (91.7%)	<0.001***
Were their adequate pain medications ordered?	3.88 (1.14); 107 (37.9%)	4.18 (1.02); 175 (62.1%)	0.016 *
Was there a chaplaincy consult ordered?	3.93 (1.13); 175 (62.1%)	4.30 (0.93); 107 (37.9%)	0.005 **
Was there a pain service consult?	4.01 (1.07); 233 (82.6%)	4.35 (1.05); 49 (17.4%)	0.013 *
Was there any consults ordered?	3.75 (1.11); 36 (12.8%)	4.11 (1.07); 246 (87.2%)	0.029 *
Psychological and psychiatric domains			
Did the patient/family have psychological care? ^a	3.55 (1.21); 11 (4.8%)	4.21 (1.00); 219 (95.2%)	0.034 *
Were the patient's wishes respected?	2.43 (0.98); 7 (5.9%)	4.50 (0.81); 112 (94.1%)	<0.001***
Were the family's wishes honored	2.80 (1.30); 5 (2.3%)	4.24 (0.96); 215 (97.7%)	0.006 **
Was there family conflict?	3.16 (1.21); 19 (38.0%)	3.90 (1.08); 31 (62.0%)	0.028 *
Was there a formal debriefing after the death?	4.22 (1.02); 175 (88.4%)	3.35 (1.43); 23 (11.6%)	0.003 **
Were the clinician needs met?	2.91 (1.06); 22 (9.6%)	4.29 (0.94); 208 (90.4%)	<0.001***
Did the clinician have unresolved needs?	4.28 (0.93); 208 (79.1%)	3.47 (1.30); 55 (20.9%)	<0.001***
Social domain			
Was the patient supported by family and friends?	3.17 (1.34); 12 (5.1%)	4.20 (1.00); 222 (94.9%)	0.003 **
Spiritual, religious and existential domains			
Did the patient and family have spiritual support?	3.77 (1.15); 22 (11.0%)	4.29 (0.93); 178 (89.0%)	0.025 *
Cultural domain			
Were the patient and families cultural needs met?	3.11 (1.17); 9 (5.4%)	4.33 (0.93); 159 (94.6%)	<0.001***
Ethical and Legal Domains			
Were there ethical / legal issues surrounding the death?	4.29 (0.90); 172 (82.3%)	3.70 (1.31); 37 (17.7%)	0.011 *
Were there ethical or legal issues surrounding goals of care?	4.13 (1.04); 261 (92.6%)	3.33 (1.24); 21 (7.4%)	0.002 **
Were there ethical or legal issues surrounding treatment?	4.12 (1.03); 265 (94.0%)	3.18 (1.42); 17 (6.0%)	0.004 **
Care of the patient at the EOL domain			
Was it an unexpected death?	4.31 (0.89); 212 (85.1%)	2.89 (1.26); 37 (14.9%)	<0.001***
Was there a transfer to higher level of care?	4.22 (0.97); 176 (88.0%)	3.62 (1.35); 24 (12.0%)	0.036 *
Was the patient alone at time of death?	4.25 (1.02); 188 (98.4%)	2.67 (1.53); 3 (1.6%)	0.025 *
Was memory making done (example footprints, locks of hair, charm)?	2.75 (1.71); 4 (1.9%)	4.27 (0.94); 209 (98.1%)	0.040 *

Survey Questions	No	Yes	p-value
Were EOL orders discussed w/MD/NP	3.67 (1.18); 125 (47.2%)	4.38 (0.84); 140 (52.8%)	<0.001***

Significance Codes:

*
<0.05,

**
<0.01,

<0.001

^a“Psychological care” was defined broadly as social work, chaplain, childlife, supportive care coordinator, PACT team, volunteers, parent liaison, psychologist or psychiatrists

Table 4

Factors which were present in a high quality dying and death identified by Clinicians

Factor	Significant positive impact on Quality
Location * where patient died *Depending on location had positive and negative impact on quality	p-value = 0.019 *
Role of the clinician-Depending on clinician role there was a positive and negative impact on quality-highest pastor, lowest RT	p-value = <.001 ***
Gender of the clinician Males rated quality higher than females	p-value = <.001 ***
Clinicians with a higher level of formal education	p-value = 0.005 **
Higher amounts of training in End of life care of the clinician	p-value = 0.006 **
The higher the quality of multidisciplinary team	p-value = <.001 ***
Clinician rated patient at peace	p-value = <.001 ***
Dying on clinician's shift (vs. within 3 days of clinicians shift)	p-value = 0.005 **

Significance Codes:

*
<0.05,**
<0.01,***
<0.001

Table 5

Exemplars of higher and lower quality dying and death experiences

Exemplars of Higher Quality Dying and Death Experiences	
	<i>"The physician was supportive in ordering morphine every time I requested it, on behalf of the parents. It was very important to the parents that the baby not suffer at all, and they did not want to experience "agonal breathing".</i>
	<i>"PICU team, oncologist, pain service for end of life, social work, family liaison. In my 30 years at ... I have never been involved in a more peaceful, supported death as this one was. The family was supported, the patient passed peacefully, and he never struggled or showed any sign of anxiety, even after we removed him from support. I would like to know why it can't always be like this"</i>
	<i>"Continuous sedatives, pain medications, with ranges and dosing increases. prn meds, alternative meds. On day of withdrawal, also had discussion and support of pain service physician, ICU MD, and plans were discussed for withdrawal."</i>
	<i>"He had a consistent group of nurses/MDs for over a month and we were able to be there to support the patient and family for the end-of-life care".</i>
	<i>"We gave family time to get into town to say their goodbyes prior to discontinuing support. The family was able to bathe their son at their request, and we discontinued support at the specified time they asked".</i>
	<i>"Long, long prayers by family pastor with people speaking in tongues and passing out ... very intense!!"</i>
	<i>"Tribal Indian elders were present at bedside for prayers".</i>
	<i>"The parents were given options and ideas for bonding and caring for their daughter, as well as options for after withdrawal. They were completely in control of the entire process. Afterward, the father stated that the death was "the way it should be", cradled on her mother's chest, in a warm and loving environment".</i>
Exemplars of Lower Quality Dying and Death Experiences	
	<i>"Some days/pm nurses did not give her medication to make her comfortable. They felt that she didn't need it. So the night I worked with her I was told that her last dose of morphine was at 2 pm. 11 pm she was crying and moaning in pain".</i>
	<i>"It was still torture to watch him suffer all night".</i>
	<i>"It was just very sad, ugly, and unexpected (for the parents)".</i>
	<i>"The days afterward is when you constantly run the images and words through your mind, wondering if you did everything possible to make it easier for the family, wondering if there's anything you could have done better, anything else you should have said... No matter what the circumstances, the nurse removing the life support still feels a bit of guilt".</i>
	<i>"I felt that we made this baby suffer even though we have not had good outcomes with other babies with the same disease".</i>
	<i>"Ethics consult was ordered; when more interventions became futile (but) the father continued to push to have them done".</i>
	<i>"Family was very angry and confused about how the patient could have died despite the medical team's efforts to help them understand the severity of the patient's illness and that he may not survive. After the patient's death, family focused anger and litigation rather than grieving and being with their child".</i>