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Perception, Knowledge and Barriers to End of Life Palliative Care among Neonatal and Pediatric Intensive Care Physicians

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Abstract

Objective: To determine perception, knowledge, and barriers to the end of life palliative care among neonatal and pediatric intensive care physicians mainly practicing in Kuwait.

Methods: This study focuses a detailed self-administered questionnaire based measurements. One hundred and ninety-two (192) Kuwait based neonatal and pediatric intensive care physicians actively evaluated the survey conducted in this study. All the inquiries during this investigation were formatted using a 5-point Likert scale. However, responses to few questions are recorded in a yes or no format as 5-point Likert scale was not applicable to those issues.

Results: The response rate was in a range of 80-85% with 157 respondents completing the survey. Of the total 157, 65% (102) were neonatologists and 35% (55) were pediatric intensivists. Thirty-two (21%) were consultant staff, and almost half (n=76, 48%) have more than ten years' experience. Only 20% had prior training in end of life palliative care, and 19% have a current guideline. Also, only 12% have access to palliative care consultation team. Four different factors from both family support and team were perceived to support the provision of palliative care of a high quality. While the involvement of multidisciplinary team, pain management and formal teaching of EOL palliative care were the major components of team factors; the family support also engaged the involvement of parents/family in EOL palliative care decision. Cultural and religious constraints, lack of palliative care team and insufficient knowledge formed as major barriers.

Conclusion: In this study, neonatologists and pediatric intensivists reiterate the importance of palliative care. They evaluated both the facilitators (perception and knowledge) and barriers (cultural and religious constraints, lack of palliative care team and insufficient expertise) that significantly impact the quality of neonates and pediatrics palliative care.

Keywords: Perception-knowledge and barriers to palliative care; End-of-life palliative care

Introduction

Palliative care is taking care of body, mind, and spirit while supporting the associated family members with an intention to improve the quality of life of newborns and their families [1]. World Health Organization (WHO) defines palliative care for children as a complete care of infants who are exposed to premature death [1]. However, because of unavailability of a standardized study definition, the definition of a palliative care is mostly based on personal interpretation, which leads to significant complications especially while dealing with previous reports. The previous report outlines an outstanding number of annual fetal deaths and numbers over one million pregnancies that ultimately lead to fetal death [2]. In the same study, a significantly higher number (close to half million) of the premature birth rate associated with congenital malformations in the United States has been reported [2]. Therefore, Neonatal Intensive Care Units (NICUs) must require detailed evaluation of the barriers associated with the palliative care to have a standard definition, which in turns will develop more comprehensive palliative care programs.

Palliative care begins as soon the illness is diagnosed and continues until the end of life (EOL) irrespective of the quality and outcome of the treatment [2]. The EOL becomes a crucial decision-making step especially when the chances of living of the newborn and the associated family members become narrow or mostly impossible. This action in principle focuses on pain and symptom management and takes total care of the patient and the related family members [2]. According to WHO world health estimates and a recent report, over 29 million people die annually that require proper palliative care and out of 29 million, at least 20 million people need palliative care at the end of life [2]. Also, over half million pregnancies either results in the premature birth of neonates or diagnosed with congenital malformations [2]. In a recent report on National Vital Statistics Reports (NVSR), Melonie Heron and co-workers have mentioned at least 3.8% of newborns die soon right after the birth or shortly after discharge from the hospital [3]. As many of these fatalities are secondary to major complications that occur during the neonatal

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period, often neonatologists take care of infants who need immediate attention [3]. These infants are most likely face challenges related to surrounding palliative and end-of-life care and hence transferred to NICUs for further treatment.

Majority of palliative or EOL studies in the past suggests that pediatric intensive care units (PICUs) present a mixed knowledge of the definition and utility of palliative care. However, we acknowledge that prior expertise on PICUs may not be comparable to NICU data as the factors that influences may differ from each other in each setting. For example, the overall percentage of post-admission clinical trials conducted in pre-matured neonates is significantly different than pediatric population [4,5]. This statement is in corroboration of the previous finding suggests that the resuscitation guidelines used either in NICU or PICU is independent of patients' age and somewhat it depends upon the location [5]. We think, this differences in the guideline is may be due to several factors as outlined below. It may be due to (1) the pattern of training that each group of providers receives or (2) the providers in each setting maintain different provider status (e.g., NICU providers and PICU providers require to sustain Neonatal Resuscitation Program or NRP status and Pediatric Advanced Life Support or PALS status respectively). These differences in training then lead to disagreement between the two groups of providers in deciding the transition period from neonatal to pediatric guidelines.

Even though palliative and end-of-life care management sounds straightforward and easy, neonatologists often found it very difficult in overcoming the challenges associated with these control [6,7]. Most neonatologists go through several practical problems such as noise and lack of privacy in NICU, non-availability of proper and defined therapy to the newborn. One of the most critical hurdles that both the neonatologists and parents face is a lengthy discussion on end-of-life care knowing the least chance of a meaningful survival [8].

This particular study was designed to assess perception, knowledge, and barriers to EOL palliative care among neonatal and pediatric intensive care physicians particularly practicing in Kuwait.

Methods

After getting approval from the Institutional Review Board of Ministry of Health (IRBMH) Kuwait, the survey was sent to at least 192 neonatal and pediatric intensive care physicians between November 2016 and December 2016. This study is based on detailed and self-administered questionnaire measurements.

Questionnaires outline

This particular survey was conducted by a group of neonatal and pediatric intensive care physicians. The questionnaire consisted of four parts: demographic and current practice, perception, knowledge, and barriers toward the pediatric and neonatal end of life palliative care practice. Assessment of physician's knowledge on the definition of palliative care was based upon the World Health Organization (WHO) consensus definitions [1] of pediatric palliative care. The majority of the questions were formatted in a 5-point Likert scale answers; others had yes or no format.

Data analysis

STATA version 14 (StataCorp, College Station, TX) was for Descriptive statistics. Statistical analyses included means, standard deviation (SD), frequency and percentages. Chi-square test and ANOVA test were used to compare categorical and continuous data, respectively. Pearson correlations were used to examine relationships between confident scales and years of experience and prior training. The results of the knowledge and barriers questions were combined to binary outcomes disagree or strongly disagree and agree or strongly agree. For all statistical analysis, a minimum score of 0.05 was considered to be significant.

Results

One hundred fifty-seven physicians completed the survey, for a response rate of 82%. Majority of the respondents had a high opinion on the need for the palliative care and felt that it should be an essential part of the training. Table 1 outlines the overall distribution of responses.

Variable	**All respondents N=157 (N%)**
Age (years)	
25-35	53 (34%)
36-45	67 (43%)
>45	37 (23%)
Gender	
Male	123 (78%)
Female	34 (21%)
Registrar and senior registrar	125 (79%)
Consultant	32 (21%)
Location	
PICU	55 (35%)
NICU	102 (65%)
Years of Experience	
<5	21 (13%)
5-10	60 (38%)
>10	76 (48%)
Prior training in EOL palliative care	31 (20%)
Available EOL policy/guideline	30 (19%)
Palliative care consultation team	10 (12%)

Table 1: Physician characteristics.

Of the total 157, 102 (65%) were neonatologists, and 55 (35%) were pediatric intensivists. Majority of the respondents were male (n=123, 78%) and female (n=67, 43%) and were between 36 and 45 years old respectively. Thirty-two (21%) were consultant staff, and almost half (n=76, 48%) have more than ten years' experience. Only 20% had prior training in EOL palliative care, and 19% have a current guideline. Also, just 12% have access to palliative care consultation team.

In this study, we found the majority of respondents were in agreement on the importance of formal education of EOL palliative care (mean score=4, SD=1) and to provide pain management and analgesia in palliative care (mean score=3.4, SD=1.3) as and when necessary.

As outlined in Table 2, a score of physicians' perception ranges from a score of 1, this refers to the least essential event to a score of 5, which indicates a significant event.

Title	Neonatologists	Pediatric intensivists	All respondents	P value
Involvement of multidisciplinary team in EOL palliative care, mean (SD)	4.1 (1.4)	3.9 (1.4)	4 (1.4)	0.309
Involvement of parents/family in EOL palliative care decision	4.2 (1.4)	4.3 (1.7)	4.6 (1.6)	0.13
Pain management and analgesia are given as part of EOL palliative care	3.4 (1.1)	3.4 (1.6)	3.4 (1.3)	0.572
Importance to formally teach EOL palliative care	4.3 (0.8)	4 (1.1)	4 (1)	0.11

Table 2: Mean and standard deviation of Physicians' perceptions.

Also, in this study, the majority felt that the involvement of both multidisciplinary teams (mean score=4, SD=1.4) and parents and family (mean rating=4.6, SD=1.6) is vital in EOL palliative care decision. Neonatal and pediatric intensive care physicians didn't differ significantly on the total scores for their perception scale.

We noticed that, overall, respondents were not very confident with providing EOL palliative care (mean score=2.5, SD=1). Also, their low confidence in managing pain or leading discussion with families were 2.7, SD=1. Neonatologists were more confident in providing EOL (mean score 2.6, SD=1 *vs.* mean score 2.2, SD=0.8; P=0.03) and in leading the discussion with families than pediatric intensive care physicians (mean score 2.9, SD=1.1 *vs.* mean score 2.2, SD=1; P=0.001). We observed a significant correlation between the cumulative mean score of the physicians 'confidence scale with increase years of experience (r=0.92; P=0.002) and with prior EOL training (r=0.9; P=0.01). The self-reported confidence score is presented in Table 3 where a score of 1 refers to least confident and a score of 5 refers to very confident.

Title	Neonatologists	Pediatric intensivists	All	P value
Confident in providing EOL palliative care	2.6 (1)	2.2 (0.8)	2.5 (1)	0.0286
Confidence in managing pain	2.7(1)	2.6 (0.8)	2.7 (1)	0.893
Confidence in leading the discussion with parents/families	2.9 (1.1)	2.2 (1)	2.7 (1.1)	0.001

Table 3: Self-reported confidence.

Majority of the respondents (80%) agreed that EOL palliative care is an active and total approach to medical care. However, it involves no active resuscitation but managing distressing symptoms. Above 2/3rd of the respondents (69%) agreed with the supplement offer of the EOL palliative care following a possible failure of therapeutic options. In this survey majority of the respondents (79%) agreed with the notion that EOL care should target to improve the quality of life of the patient and his/her family. Nearly half of the physicians (49%) agreed that EOL care is appropriate following a poor neurological outcome. Physicians' overall knowledge of EOL palliative care is summarized in Table 4.

Title	Neonatologists	Pediatric intensivists	All respondents	P value
EOL implies active and total approach to medical care	83 (81%)	43 (78%)	126 (80%)	0.677
EOL can be initiated when all curative options have failed	73 (71%)	36 (65%)	109 (69%)	0.47
EOL means no active resuscitation but managing any distressing symptoms	85 (83%)	41 (74%)	126 (80%)	0.211
EOL aims at improving quality of life for the patient ad family	83 (81%)	41 (74%)	124 (79%)	0.412
EOL can be introduced for a devastating neurological outcome	44 (43%)	33 (60%)	77 (49%)	0.047

Table 4: Physicians' knowledge of EOL palliative care (agree or strongly agree).

In this study, half of the respondents (55%) reported that there are barriers to providing EOL palliative care. The main obstacles are cultural and religious constraints (87%), lack of palliative care team (81.5%) and insufficient knowledge (80%). Two-thirds felt that prognosis uncertainty is also considered a barrier toward EOL palliative care. Moreover, half of the physicians (55%) felt the risk of the diagnosis and staff disagreement about treatment plans as potential barriers. In Table 5, we have summarized the list of all possible perceived obstacles and reaction of Neonatologists and Pediatric intensivists' response to it concerning their agreement or disagreement.

Barriers	Neonatologists	Pediatric intensivists	All	P value
Barriers in EOL care	54 (53%)	33 (60%)	87 (55%)	0.407
Uncertainty of the prognosis	71 (69.5%)	35 (64%)	106 (67.5%)	0.799
Uncertainty of the diagnosis	51 (50%)	35 (64%)	86 (55%)	0.187
Conflict about treatment plans	49 (48%)	38 (69%)	87 (55%)	0.297
Lack of palliative care consultation team	85 (83%)	43 (78%)	128 (81.5%)	0.701
Cultural and religious constrain	89 (87%)	48 (87%)	137 (87%)	0.673
Insufficient knowledge	83 (81%)	42 (76%)	125 (80%)	0.534

Table 5: Perceived barriers (agree or strongly agree).

Discussion

The results of this study highlight the perception, knowledge, and barriers to the end of life palliative care among neonatal and pediatric intensive care physicians in Kuwait region. This research focuses and combines both the positive and negative factors that will eventually allow a dual approach to address both barriers and facilitators of the palliative care in all future studies. Despite some recent studies on palliative care in pediatric intensive care units (PICUs), knowledge of beliefs and practices primarily in a NICU setting is sparse [9-11]. To obtain a comparable response from neonatologists and pediatric intensivists, in this study we have defined palliative care as appropriate and approved by World Health Organisation. Also to our best knowledge only a few studies including the current study have described both barriers and facilitators [12,13].

In corroboration to the findings by Sawyer et al. [5], our results suggest that the standard guidelines used for infant CPR in the NICU, PICU, and CICU are rely on location, and not patient factors (e.g., age of the patient). Also, results from this study suggest that perceived barriers may differ from a NICU setting to that PICU setting, an observation made by several different groups earlier [14-16]. While palliative care research from this study has shed some light, it limits the generalizability to other regions because of the regulatory issues from IRBMH. One of the significant differences between our research and most of the study conducted in the United States is that, usage of medication during the care in fewer variables in the United States than in most of the Middle East countries. Also, neonatologists in middle-east regions take all the efforts that make the neonate survive irrespective of the prognosis [17,18]. It is noteworthy that regardless of the benefits of the collaborative international studies, observations made in different countries cannot be generalized because of differences in the medical practices and local administrative guidelines.

Regional factor also contributes adversely especially when the returning neonates visit their local hospitals. It is often evidenced by lack of staff and adequate care even though it is easy for the immediate family members to access the hospital [19]. In our opinion, this situation makes the neonatal care more complicated especially when the local nurses decide whether or not the neonates will be transferred to the local hospital. As discussed by Kilkulen M and coauthors, the use of telemedicine and the use of documented guidelines are the most critical factors that facilitate the smooth transfer of neonates to a palliative care unit close to their home [19-21].

We believe that a better understanding of all future practices focusing on different barriers and facilitators is essential for an improved palliative care and, end-of-life programs. In the current study, we have demonstrated that most of the neonatologists and pediatric intensivists realize the importance of palliative care just by experiencing death cases directly in NICUs. In corroboration with previous studies, neonatologists and pediatric intensivists in this study attest the difficulties in handling palliative care in the emotional level. As mentioned in Table 3, the majority of the neonatologists (and not pediatric intensivists) have expressed their comfort and necessities of palliative care. However, there still exists room for further improvement and quality in both palliative and end-of-life care as described by Romesberg et al. [15]. Nevertheless, our study reports mostly positive experiences on current practices and opinion on palliative cares and provides an opportunity for exploring the perceptions in a unique situation, being a regional study. However, we acknowledge that the sample size in the current study is relatively small. Even though it may be a potential pitfall of the study, data obtained in this study is consistent with the observation by other communities as discussed above. Overall, data from this study represent the necessities of palliative care, especially in culturally sensitive regions.

Conclusion

It is widely accepted (irrespective of the type of practice adopted in different countries), that palliative and end-of-life care is associated with many barriers and mostly happen at the eleventh hours. Data from our study indicate that neonatologists and pediatric intensivists believe that with the advancement of technologies, palliative care can definitely enhance the quality of treatment in critically ill newborns with poor prognosis. As mentioned above, palliative care can be of emotionally challenging and may bring differences in the opinion among coworkers, but most participants feel confident on its overall abilities. However, improved implementation strategies are definitely required to address various barriers as discussed in this report. Also, there is definitely a need of further exploration of formalized palliative care programs in order to provide high quality care to neonates and their corresponding family members with life-limiting threat.

References

1. World Health Organisation. Cancer: WHO definition of palliative care.
2. MacDorman MF, Kirmeyer S (2009) Fetal and perinatal mortality, United States, 2005. Natl Vital Stat Rep 57: 1–19.
3. Heron M, Hoyert DL, Murphy SL, Xu J, Kochanek KD, et al. (2009) Deaths: Final data for 2006. Natl Vital Stat Rep 57: 1–134.
4. Ali N, Sawyer T, Barry J, Grover T, Ades A (2017) Resuscitation practices for infants in the NICU, PICU and CICU: Results of a national survey. J Perinatol 37: 172-176.
5. Sawyer T, Clark A, Ridout R (2009) Infant resuscitation outside the delivery room inneonatal-perinatal and pediatric critical care fellowship programs: NRP or PALS? Results of a national survey. J Neonatal-Perinatal Med 2: 95–102.
6. Lantos JD, Tyson JE, Allen A, Frader J, Hack M, et al. (1994) Withholding and withdrawing life sustaining treatment in neonatal intensive care: Issues for the 1990s. Arch Dis Child Fetal Neonatal Ed 71: 218–223.
7. McHaffie HE, Cuttini M, Brölz-Voit G, Randag L, Mousty R, et al. (1999) Withholding/withdrawing treatment from neonates: Legislation and official guidelines across Europe. J Med Ethics 25: 440–446.
8. Singh J, Lantos J, Meadow W (2004) End-of-life after birth: Death and dying in a neonatal intensive care unit. Pediatrics 114: 1620–1626.
9. Burns JP, Mitchell C, Griffith JL, Truog RD (2001) End-of-life care in the pediatric intensive care unit: Attitudes and practices of pediatric critical care physicians and nurses. Crit Care Med 29: 658–664.
10. Davies B, Sehring SA, Partridge JC, Cooper BA, Hughes A, et al. (2008) Barriers to palliative care for children: Perceptions of pediatric health care providers. Pediatrics 121: 282–288.
11. Jones PM, Carter BS (2010) Pediatric palliative care: Feedback from the pediatric intensivist community. Am J Hosp Palliat Care 27: 450–455.
12. Epstein EG (2010) Moral obligations of nurses and physicians in neonatal end-of-life care. Nurs Ethics 17: 577–589.
13. Kain V, Gardner G, Yates P (2009) Neonatal palliative care attitude scale: Development of an instrument to measure the barriers to and facilitators of palliative care in neonatal nursing. Pediatrics 123: 207–213.
14. Carter BS, Levetown M, Friebert SE (2011) Palliative care for the infants, children, and adolescents: A practical handbook. John's Hopkins University Press, Baltimore.
15. Romesberg TL (2007) Building a case for neonatal palliative care. Neonatal Netw 26: 111–115.
16. Carter BS (2004) Providing palliative care for newborns. Pediatr Ann 33: 770–777.
17. Bilgen H, Topuzoğlu A, Kuşçu K, Altuncu E, Ozek E (2009) End-of-life decisions in the newborn period: Attitudes and practices of doctors and nurses. Turk J Pediatr 51: 248–256.
18. Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, et al. (2000) End-of-life decisions in neonatal intensive care: Physicians' self-reported practices in seven European countries. EURONIC Study Group. Lancet 355: 2112–2118.
19. Kilcullen M, Ireland S (2017) Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. BMC Palliat Care 16: 32.
20. Twamley K, Craig F, Kelly P, Hollowell DR, Mendoza P, et al. (2013) Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom. J Child Health Care 18: 19–30.
21. Korzeniewska-Eksterowicz A, Respondek-Liberska M, Przysło L, Fendler W, Młynarski W, et al. (2013) Perinatal palliative care: Barriers and attitudes of neonatologists and nurses in poland. Sci World J 2013: 1-7.