International Journal of Science and Research (IJSR)
ISSN: 2319-7064
Impact Factor 2024: 7.101

End of Life Care for Children: The Knowledge and Perceptions of Pediatric Health Care Providers in a Tertiary Care Hospital in a Developing Country

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Abstract: ***Background**: Adding quality care to end-of-life (EOL), rather than aiming solely to put more time into the remaining life, strives to put more life into the remaining time. End-of-life decisions range from decisions to forgo potentially life-sustaining treatments and decisions to alleviate pain or other symptoms by using drugs with a possible life-shortening effect. End-of-life decision making for children typically involves caregivers, parents, and, if possible, the child. **Materials and methods**: An exploratory cross sectional survey of pediatric health care providers (HCP) working in pediatrics department of a tertiary care institute regarding their knowledge and perceptions on EOL care in children was conducted using a pre-tested semi structured anonymous questionnaire in three sections with 12, 16 and 11 items respectively. The study protocol was approved by the Institute Ethics Committee. **Results**: Majority of the respondents were nurse, 98/118 (83.1%). The major components of EOL as reported by respondents were: psychological/emotional support to parents (38.13%), pain management (29.66%) and comfort/physical needs/ADL (24.57%) etc. Majority of the health care personnel, 109/118 (92.4%) were in favor of a written protocol for EOL care. **Conclusion**: Regarding EOL care aspects there is a wide variation in knowledge and perceptions of health care providers working in pediatric setting. There is a need for an awareness regarding legal policies/ specific laws that are relevant to the following EOL issues. A written protocol or a training program may be more helpful in rendering EOL care.***

Keywords: End of life care, end of life decisions, children, health care providers

1. Introduction

Death is an everyday occurrence in the critical care units, which we all wish to be peaceful and to occur in the presence of loved once, has become artificial and away from the family in the critical care units. [1] End of life is defined as a phase of life when a person is living with an illness that will worsen and eventually cause death. Good clinical care can prevent or alleviate suffering for many patients at the end of life by assessing symptoms and providing psychological and social support to the patients and their families [2]. In western countries end-of-life decisions played a role in 23% to 51% of all deaths. [3] In pediatric ICUs retrospective studies in last decade suggests that 40-60% of all deaths follow an End-of-life (EOL) decision. [4] They range from decisions to forgo potentially life-sustaining treatments, alleviate pain or other symptoms by using drugs with a possible life-shortening effect, to give assistance in dying, that is, the use of drugs with the aim of ending life. [5]

Parents' perception of their child's suffering is an important factor in their projected decision making. [6] In a study regarding experiences and attitudes of European intensive care nurses regarding EOL care, majority of nurses (91.8%) indicated direct involvement in EOL patient care, while 73.4% reported active involvement in decision-making process. [7] Residents reported more than average competence in 50% of EOL care competencies listed in a recent study. [8] In light of all this the current study focuses on the knowledge and perceptions of pediatric health care providers (HCP) regarding end of life care for children.

2. Background

End of life is a phase of life when a person is living with an illness that will worsen and eventually cause death. It is not limited to the short period of time when the person is moribund. Excellent end-of-life care, rather than aiming solely to put more time into the remaining life, strives to put more life into the remaining time. In pediatric settings care for children with advanced life-threatening conditions, limitation of interventions (LOI) orders typically address aspects of do-not-resuscitate orders and can also specify limitations on other medical interventions. [9] In developing countries the most common modes of life-support limitation practiced were withholding new treatments (17/31; 54.8%) and 'do-not-resuscitate orders' (14/31; 45.2%).[10] The intentions of such orders are to prevent suffering and promote comfort, quality of life, and dignity. [11]

There are few studies in Indian setting exploring the knowledge and perceptions of pediatric health care providers regarding end-of-life care. The present study has been undertaken in view of identifying the perceptions of health care providers regarding various aspects of end-of-life care of children in Indian scenario for provision of better quality care.

DOI: https://dx.doi.org/10.21275/SR25309225909

3. Materials and Methods

An exploratory cross sectional survey was used for the present study. Total enumeration technique was used to enroll the subjects for the study. A total of 118 health care providers (HCP) comprising of nurses and residents working in neonatal, pediatric medicine and surgical units of a tertiary care institute were contacted for the study. A pretested anonymous questionnaire in three sections with 12, 16 and 11 items respectively was used to assess their knowledge and perceptions on EOL care in children. The questionnaire was developed after reviewing EOL care literature. A draft questionnaire was prepared and submitted to 5 experts in fields of pediatric medicine and nursing for their views. Validity of the tool was established through the opinion of subject experts. Reliability of the tool was established by test retest method. Pilot study was conducted on five pediatric HCP and then modified further. The approximate time taken to answer the questionnaire was 25 minutes.

The demographic characteristics of the health care personnel were collected using subject data sheet. The section-I of the questionnaire, including items like health care provider, job title, professional education, work area, experience, number of EOL cases attended in last one year, training/workshop attended and their practical difficulties in providing EOL care. The section II was used to assess the knowledge of HCP regarding EOL care with eight statements for their agreement or disagreement with EOL care aspects. The perception of HCP was the main focus in Section III with a case scenario for their response. The study protocol was approved by the Institute Ethics Committee. The responses were collected and analyzed in descriptive statistics using SPSS 17.0 software.

4. Results

Characteristics of health care providers

Out of 118 health care providers to whom the questionnaire was administered, majority were nurses 98 (83.1%) and 20 (16.9%) physicians completed the questionnaire. The mean age and clinical experience of the respondents was 33.01±8.141 and 8.30±7.188 respectively. Majority 80.5% (95) of the respondent were female, 69/118 (58.5%) carrying a job title of Grade II nursing staff. Regarding professional education, 57/118 (48.3%) were graduates (out of 20 responded physicians, 6 mentioned their professional education as graduation) followed by diploma (39.8%) and post graduation (11.9%). Pediatric medicine ward was the main work area as responded by the health care providers (37.3%). Out of 118 respondents 48 (40.7%) attended less than 5 EOL cases in last one year and only 11% (13/118) had undergone any training/workshop regarding EOL after professional education. Regarding any practical difficulties in providing EOL care to majority i.e.77.1% (91) health care providers reported none in their clinical setting during last one year. The characteristics of the respondents have been described in **Table 1**.

Table 1: Characteristics of health care providers working in Pediatric settings (N=118)

Variable		f (%)
Health care personnel	Physician	20 (16.9%)
	Nurse	98 (83.1%)
Sex	Male	23 (19.5%)
	Female	95 (80.5%)
Job	Senior resident	8 (6.8%)
	Junior resident	12 (10.2%)
	ANS	7 (5.9%)
	Gr I Nursing staff	22 (18.6%)
	Gr II Nursing staff	69 (58.5%)
Professional education	Diploma	47 (39.8%)
	Graduation	57 (48.3%)
	Post graduation*	14 (11.9%)
Work area	Pediatric medicine ward	44 (37.3%)
	Pediatric surgery ward	27 (22.9%)
	Neonatal ICU	12 (10.2%)
	Pediatric Surgical ICU	22 (18.6%)
	Pediatric Intensive care unit	13 (11%)
No of EOL cases attended	Nil	2 (1.7%)
	<5	48 (40.7%)
	05-10	33 (28%)
	>10	35 (29.7%)
Previous training/ workshop/class	Yes	13 (11%)
	No	105 (89%)
Difficulties in providing EOL care	Yes	27 (22.9%)
	No	91 (77.1%)
	Mean±SD	**Range**
Age	33.01±8.141	21-56 years
Experience	8.30±7.188	1-30 years

Post graduation*- out of 20 physicians responded, 6 mentioned their professional education as graduation.

Knowledge of health care providers regarding end of life care

Table 2: Pediatric health care provider's understanding regarding EOL care and its components.

	Response	**f (%)**
HCP's understanding regarding EOL care	1. Provide comfort and dignity to a child has no further survival chance	5 (6.49%)
	2. Improves QOL of patient and family who face life threatening illness	3 (3.89%)
(N=77)	3. Peaceful psychological preparation of parents	5 (6.49%)
	4. Care of patient approaching death or terminally ill	**47 (61.03%)**
	5. Pain management, peaceful death, psychological counseling for family members	4 (5.19%)
	6. Condition in which all vital organs further reach to end of life/children with poor prognosis	3 (3.89%)
	7. Period of time of disease or disability that progressively worse until death	1(1.29%)
	8. EOL focus on the palliative care of terminally ill symptoms	9 (11.68%)

Components of EOL care	**1. Comfort/physical needs/ADL**	**29 (24.57%)**
	2. Care with dignity/QOL/privacy	10 (8.47%)
(N=118)	**3. Psychological/emotional support to parents**	**45 (38.13%)**
	4. Pain management	**35 (29.66%)**
	5. Treatment of symptoms/ prevent complications	11 (9.32%)
	6. Palliative care/supportive care	24 (20.33%)
	7. Counseling	4 (3.38%)
	8. Peaceful death	2 (1.69%)
	9. Nutritional support	6 (5.08%)
	10. Airway, breathing, circulation, disability	2 (1.69%)
	11. Treating team with family	1 (0.84%)
	12. Supportive services	2 (1.69%)
	13. Knowledge	1 (0.84%)
	14. Medications	5 (4.23%)
	15. Financial support	2 (1.69%)
	16. Ventilator support	4 (3.38%)
	17. Rehabilitation	1 (0.84%)

"Care of patient approaching death or terminally ill" was the response of many of the health care providers (61.03%) for their understanding regarding EOL care. The major identified components of EOL care were psychological/emotional support to parents (38.13%), pain management (29.66%) and comfort/physical needs/ADL (24.57%) etc. The responses of the HCP regarding EOL care and its identified components have been described in **Table 2**.

Providing comfort and dignity was identified as the primary goal of EOL care by majority of the respondents (86.4%). Sixty six (55.9%) HCP reported that parents of children who are approaching the end of life/critically illness have the right to receive or refuse the treatment. Responses related to palliative care for the child with terminal illness includes controlling pain, relieving other systems of disease, provide emotional and psychological comfort as reported by HCP was 73.7%. The justice and beneficence were stated by the subjects (32.2%) as the violation of two main ethical principles while failure to address the suffering of a child with terminal illness. DNR order is acceptable in children or babies, for them CPR may not provide benefit as reported by the respondents (40.7%).

Majority of the respondents (66.9%) reported that both family and medical team are responsible for making the decisions regarding the EOL care and treatment aspects of the child. There is a wide variation in awareness regarding legal policies/ specific laws related to EOL issues such as: DNR orders (23.7%), limitation of therapy (9.3%), brain death (19.5%), organ donation (26.3%) and euthanasia (22.9%). The health care providers' agreement or disagreement with EOL care related statements is described in **Table 3**.

Table 3: The health care providers' agreement or disagreement with EOL care aspects **(N=118)**

S. No	Statement	Major response f (%)	Health care personnel	f (%)
1	Families and health care professionals have no obligation to work together to make compassionate decisions for the child.	Disagree 72 (61.0%)	Physician	16 (22.2%)
			Nurse	56 (77.8%)
2	Life sustaining treatments already commenced for the child may be withdrawn subsequently if decided appropriate.	Agree 82 (69.5%)	Physician	14 (17.1%)
			Nurse	68 (82.9%)
3	Clinical deterioration or unresponsive to treatment to parents or parents' decision to limit treatment is the beginning of EOL decision making	Agree 61 (51.7%)	Physician	11 (18%)
			Nurse	50 (81.96%)
4	Request of parents to continuing treatment for the child despite the clinical deterioration even with optimal therapeutic intervention is appropriate.	Agree 94 (79.7%)	Physician	18 (19.14%)
			Nurse	76 (80.85%)
5	Before taking the final decision for withdrawal of treatment for the child, it is not legally important to seek the medical opinion of second specialist.	Disagree 87 (73.7%)	Physician	18 (20.68%)
			Nurse	69 (79.31%)
6	Analgesia and sedation provided to the child by any route for relieving pain, an unwanted symptom is appropriate.	Agree 73 (61.9%)	Physician	13 (17.80%)
			Nurse	60 (82.19%)
7	Consent of person responsible for the care of the child (parent/significant member of the family) is not required in relation to the provision of minor or major medical treatment.	Disagree 103 (87.3%)	Physician	17 (16.50%)
			Nurse	86 (83.49%)
8	The person (parent/significant member of the family) responsible for the care of child, who is approaching end of life and cannot speak for himself may seek DNR on behalf of the child.	Agree 84 (71.2%)	Physician	17 (20.23%)
			Nurse	67 (79.76%)

Health care providers' perception regarding end of life care

When providing information to the parents/family member regarding EOL care of a child, 48 (40.7%) were in favor of explaining the details on the basis of parents' education and expectation and type of disease and its severity. When the health care providers were asked about their response for refusal of treatment/care by a competent parent, 79 (66.9%) opined that they will try their best to explain to the parents, and accept their decision.

In a situation where analgesia or sedation to be used, ninety (76.3%) respondents reported discussing its purpose with the parents while twenty (16.9%) never discussed this issue with parents/child. For making decision regarding the limitation of therapy (LOT) for a child whose survival was unlikely, 41 (34.7%) health care providers reported that LOT is ethical and acceptable. For discussing the EOL care aspects with the parents, general care and support (63.6%), medications including analgesia (33.1%), nutritional support (26.3%) and life sustaining measures (44.1%) were cited as important by the respondents.

For a case scenario (A 7 year old male child diagnosed as a case of ALL, admitted in the pediatric unit due to bleeding and respiratory failure. Now the child is in deep coma and being supported by mechanical ventilation. Child having no relatives, brought by the orphanage staff and they insisted on cessation of further treatment and withdrawal of life support. What in your opinion should the health care provider do?), seventy three (61.9%) respondents were in favor of continuing all active support/ treatment and explaining about child's condition to the caretakers.

Majority of the respondents, 114/118 (96.6%) reported that a written protocol would be beneficial in providing effective end of life care in clinical settings and 109 (92.4%) found that a training program can teach more about end of life care and its issues in health care areas. For making decisions regarding end of life care, 107 (90.7%) reported that a full participation of treating team (physician, nurse, physiotherapist and respiratory therapist) is necessary along with parents. Majority of HCP 41(34.7%) felt comfortable while caring children with end of life conditions and talking to the parents/family members regarding end of life care issues.

5. Discussion

A previous study showed that parents rated physician care for their dying child more highly when the physicians gave clear, unambiguous information about what to expect at the end-of-life period including symptoms. This shows that parents benefit from the information, feeling as prepared as is possible for the end of their child's life and those clinicians can help parents to achieve this benefit. So exploring the knowledge and perceptions of the health care providers are significant in provision of high quality end of life care in pediatric settings.

The present study we found that there is a wide variation in their perceptions for end of life care aspects. Most of them are aware about end of life care and its major components. In the present study controlling pain, relieving other systems of disease, provide emotional and psychological comfort identified as the major components of end of life care for children. Studies from developed countries also show similar findings [12, 13]. Majority of the respondents in the present study reported both family and medical team are the responsible persons for making the decisions regarding the EOL care and treatment aspects of the child, as cited in various studies [6, 14]. Most of the health care providers are not aware of the legal policies/ specific laws related to end of life care issues.

Studies reported that from the practical point of view extensive serial discussions with the family members are required to achieve consensus regarding end of life decisions [14, 15, 16]. In this study also respondents were in favour of explaining the parents about the condition of child and care to be provided and finally accepting their decisions including refusal of treatment/care by competent parents if any.

Palliative care for the child with terminal illness includes controlling pain, relieving other systems of disease; provide emotional and psychological comfort as reported by majority of our study participants. These components of the palliative care should be managed in an ethical manner as reported in a recent study [17, 18] Physicians and nurses who are caring for terminal patients within palliative care settings in India can be expected to be much more knowledgeable about the care aspects such as pain control and sedation [19]. Studies suggest that it is important to consider the whole family system in order to meet the complexity of the situation of a family with a critically ill child or adolescent [20]. This is in line with our study result as discussing the EOL care aspects with the parents, general care and support, medications including analgesia, nutritional support and life sustaining measures were cited as important by the respondents.

In a study regarding parents' priorities and recommendations related to EOL care, the parents were clear that honest and complete information needs to be forthcoming and shared with families. We found that forty eighty subjects were in favor of explaining the details of EOL care aspects on the basis of parents' education and expectation and type of disease and its severity. Nurses are in an ideal position to help coordinate communication among members of the health care team, including interdisciplinary care providers, family members, and the ill child [21]. Recent literature shows that poor physician communication often created misconceptions regarding the quality of life and longevity expectations and hindered patients' and/or surrogates' ability to make informed decisions [22].

Autonomy, beneficence, non-malfeasance, justice, dignity, veracity and honesty are the major ethical principles related to the care of a critically ill child in clinical setting. We found that justice and beneficence were stated by the respondents as the violation of two main ethical principles while failure to address the suffering of a child with terminal illness. In the present study regarding decision making in EOL care aspects of a child majority of the respondents opined that both family and medical team are responsible and a full participation of treating team (physician, nurse, physiotherapist and respiratory therapist) is necessary along with parents. Similar findings were reported from studies from developing countries[10].

Regarding legal policies/ specific laws related to EOL issues such as DNR orders, limitation of therapy, brain death, organ donation and euthanasia, only limited number of respondents expressed awareness. Shaw et al [23] in their study found that most respondents wanted to be involved in children's EOL care and few of them rated themselves as having high confidence, knowledge or support to provide EOL for children and these perceptions were unrelated to years of experience or special interests.

Sedative drugs in end of life care for palliative sedation are commonly prescribed to control refractory symptoms and relieve unbearable suffering [24]. It should be used with extreme caution, together with regular multidisciplinary discussions, specialist psychological support and spiritual assistance [25]. In our study regarding administration of sedation/analgesia majority of the health care personnel showed their interest in discussing its purpose with the parents. The decision to withdraw or withhold a medical treatment is more complex and difficult than the decision to commence or continue treatment [26]. For making decision regarding the limitation of therapy (LOT) for a child whose survival was unlikely, 34.7% health care providers reported that LOT is ethical and acceptable. Studies reported that from an ethical and legal point of view, any treatment that does not provide net benefit to the patient may be withheld or withdrawn, and the goal should be shifted to the alleviation of existing symptoms. [27]

Because of the numerous years of deficiencies in teaching EOL aspects in teaching institutions, nurses are working in hospitals, clinics, and community settings without the knowledge of how best to assist patients and families facing the end of life [28]. It is evident from the literatures that despite the growing importance of end-of-life care and the need to improve it, physicians receive limited systematic training in end-of-life care [29]. Kesselheim J C et al in their study found that physicians reported limited confidence in confronting several ethically challenging situations, especially with respect to issues that arise in pediatric end-of-life care and research ethics [30]. In the present study majority of the respondents,(96.6%) reported that a written protocol would be beneficial in providing effective end of life care in clinical settings and 92.4% found that a training program can teach more about end of life care and its issues in health care areas. Training and clinical guidance may be viewed as a means to help health care personnel better cope with the problems related to end of life care. [31]

In our study majority of health care providers in the present study felt comfortable while caring children with end of life conditions and talking to the parents/family members regarding end of life care issues. While studies from developed countries reported that suffering at end of life (EOL) adds complexity to the challenges faced by health care providers in caring for dying children and their families [32, 33].

This study has some limitations. The study was limited to a cross sectional survey design i.e. the data was only collected at one point of time which limits the generalization of the findings. The survey relies on the self reports and views of a relatively small number of health care providers from the pediatric department at one tertiary care hospital, which may not be very accurate. Though the total enumeration technique was used for sample selection, but researchers could not contact all due to their non-availability at the time of survey. The perceptions of the parents regarding end of life care along with that of health care providers would strengthen the study results. There is always a room for debate about whether all health care providers should be confident enough in dealing with the entire array of end of life care aspects and its issues. Even in light of the aforementioned limitations we believe that this study has several implications for health care providers and researchers**.** Since the end of life care of children required specialized training in managing its different aspects, there is a definite need for training for health care providers in pediatric setting. The study demonstrates a need to augment the EOL care practices by the use of a written protocol in every unit.

6. Conclusion

In summary the present study demonstrates the knowledge and perceptions of pediatric health care workers in a tertiary care hospital in northern India. As many of the health care providers are aware of various aspects of EOL care, except in areas like legal policies/ specific issues, the present study recommends a well scheduled training program/ a written protocol for all health care providers for managing EOL cases.

Conflict of interest

Authors declare no conflict of interest.

Future Scope

1) Future studies can focus on creating clear guidelines for end-of-life (EOL) care in pediatric settings.
2) Training programs should be developed to improve healthcare providers' knowledge of EOL care.
3) More research is needed on legal and ethical awareness regarding DNR orders and euthanasia.
4) Parents' role in decision-making should be studied to improve communication and patient care.
5) Healthcare workers need better emotional support to handle the stress of EOL care.
6) Palliative care should be better integrated into pediatric hospitals for improved patient comfort.

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