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Original Research

End of Life Care in Pediatrics: A Family Centered Care Approach

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Abstract

Background:

The purpose of this study was to End of Life Care in Pediatrics: A Family Center Care Approach by compiling a clinical guide. The comparative method was multi-stage. The statistical population in this study was the people in the focus group and nurses working in the pediatric ward of hospitals affiliated to Mashhad University of Medical Sciences, Shahid Beheshti Medical Sciences of Tehran, Shiraz Medical Sciences, Isfahan Medical Sciences and Birjand Medical Sciences. Convenient and available sampling method was available as many as 100 people. The data collection instrument was a three-part questionnaire, including pre-mortem, in-child and post-mortem care. Responses were calculated using a round scale from inappropriate to appropriate with a score of one to nine. The content validity method was used to confirm the validity of the questionnaire and the round fit method technique was used for checking the reliability. The results of this study provided nurses with appropriate guidance to make more informed decisions regarding the challenges of providing nursing care in the later stages of children's lives and supporting parents and other family members, and to improve the quality-of-service delivery.

Keywords: End of Life, Pediatrics, Family Centered Care

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Introduction

The child is the product of the cohabitation of the parents. Parents who are united by a bond and form a loving and loving center called the family. Children have the right to life, growth, perfection and other worthy human rights. Children make up the vast majority of billions of human beings on the planet; in addition to being the foundation of society, they are the most sensitive and vulnerable group in society, and their issues need special attention. Obviously, ensuring the health of this most valuable human capital should be one of the first and most important duties of any nation and one of the main programs of any government(1). Nursing force is one of the most important human resources and is the largest part of the staff in health care that strives to meet patients' special needs in specific situations and its ultimate goal(2).

Children are a symbol of health and hope, and their death calls into question the true meaning of life. Despite the daily death of children, for many people the death of a child is an unimaginable phenomenon (3). With recent advances in medical knowledge, life expectancy in human societies has increased so that in the last 4 years more than 2% of the cases that led to death survived and many patients who were previously sentenced to death can live longer. Have a longer life (4) Unfortunately, 22% of chronic patients eventually die and need care in the later stages of life. In addition, with the control of the disease and increase the life expectancy of patients with acute and chronic disease, the need for end-of-life care for these patients increases (5).

End-of-life care is an important approach in the comprehensive care of patients with incurable diseases and aims to achieve the best quality of life for patients and their families. In the final stages of life, most treatments are stopped and doctors they no longer continue treatment or start new treatment (6). There is no clear definition of the end of life. The final few days of life when a person is irreversibly dying are generally referred to as the end of life, also known as the final phase. End-of-life patient care has always been at the heart of palliative care (7). At this stage, child care comes first, which includes physical, mental and spiritual care. Children in the later stages of life often have no cure for them, and in some cases even continuing treatment for the child is more harmful than helpful, but in some cases the parents are very insistent on continuing the same treatment and say: We do not want to lose hope and demand treatment for their child despite the fact that it is harmful (8).

It is clear that parents want the best care for their children and avoid anything that reduces it. That is why they often ask for highly aggressive treatment for their children so that they are never accused of being bad parents. In some cases, they worry that if they only agree to take care of their child, they have not made the right choice and have not done something for their child in accordance with the love and affection they have for them. They want their interest in their child to be seen. And the only way to show their interest in the child is to continue treatments for the child (9).

In some cases, the primary goal in caring for dying patients is to reduce symptoms and improve quality of life for the rest of their lives. And in general, the goal of end-of-life care is to achieve the best possible quality of life for patients, family and friends in the final stages of a sick child's life (10). Dying Patients usually have a number of medical problems and require life-prolonging measures as part of their treatment plan, and in some cases they have to decide whether to discontinue treatment or prolong their life (11).Among the members of the treatment team who have the most conflict with the child's family, nurses are in the best position to reassure them by demonstrating family authority. The nurse's first responsibility is to pursue family aspirations. It is best to coordinate with your doctor, but the nurse does not need to initiate it. When discussing difficult issues begins, the nurse should allow the child and family to express indirect opinions about uncertainty or concerns about the course of care(12). Nurses should answer questions honestly and, if unable to answer, reassure the family that they will arrange a consultation with the physician. It is important that nurses address any ambiguities or misunderstandings about the disease to the child and family To clarify(13).

In some cases, accepting or rejecting treatment is inextricably linked with hope and despair, so that the family sees the lack of continued treatment or accepting aggressive treatments in the shadow of hope or despair, and the shadow of this view on parents' decisions is so much that parents instead Decide on the patient and choose the best decision for him based on his hopes and needs(14). n important determining factor in deciding whether to end a child's life and those with a critical illness is to consider the child's age, pre-disease cognition level and level of function, pain or discomfort, the child's chances of survival, and quality of life. Accepting the death of a child is a great crisis for parents, which leads to a change in the life of the parents. More than 6,000 children die each year in the United States, the death of a child is a deep and fundamental loss, it is very hard to bear because parents are in contact with their child throughout their lives, even before the child is born, the future parents Imagine their baby and the expectations and aspirations they can provide for them(15).

Materials and Methods:

In this study, using the programs of other countries and asking for opinions from domestic experts using the Delphi technique in compiling a clinical guide to end-of-life care in children with a family-centered approach, a multi-stage comparative study was used to tailor a clinical guide. To design with the culture of our country in the field of end-of-life care in children with a family-centered approach. Approved with Ethical Code IR.KHUISF.REC.1393 this study, the Delphi method was used to compile the final questionnaire. First, the members of the focus group were selected according to their experience and expertise in relation to the research topic, which was about 15 people, and the initial questionnaire was sent to them via email. After 5 days, all questionnaires (100%) reached the researcher and the ambiguities and problems raised by the experts were resolved. After the corrections made based on the experts' opinion regarding the problems and ambiguities, a questionnaire was sent again to confirm the service of the focus group, which returned after 5 days (100%). According to the confirmation of the appropriateness of the questionnaire from the perspective of experts, the final questionnaire was developed. used. Nice is part of the UK National Health Service and a clinical guide organization that provides evidence-based advice for the care of people and, in some cases, due to a lack of evidence, the clinical guide developers use it to develop it.

Based on this model, four stages are compiled:

1- Information collection stage: in this stage, the information required for research is collected
2- Writing stage: In this stage, it is about the subject itself and the researcher seeks evidence and examines the evidence which is obtained from reputable sources and sites cand is the formation of a group of researchers and specialists to begin the development and drafting of clinical guidance. The collected in the previous stage will be consulted and agreed upon by this reviewed group, and the cases that have differences will be identified and revised according to the recommendations. To complete the clinical guide from the group of experts, the people involved,

Patients are used. 4- Dissemination stage: In this stage, the clinical guide is published after the defense and its approval by the university and is provided to the nurses.

Data Collection tools

1- Review of advanced texts including guides, standard clinical guidelines in the field of end-of-life care

Browse advanced texts using articles, guidelines and standards in the world in the field of end-of-life care, use related keywords to search among articles with similar topics to achieve research goals.

2- Final modification of the clinical guide based on the opinion of experts

After collecting the data, the clinical guide components were sent as separate items to review and confirm the service of the expert group to make the necessary corrections and complete the clinical guide (nominal group).

In the final stage, a group of specialists (professors) was invited during the meeting to discuss and conclude and approve the clinical guide. Using the opinion of experts, the final modification of the clinical guide was done and after the final approval, the clinical guide was compiled. (Focus group).

- How to do it

In the first stage, the library and electronic methods were used, so that the related keywords were done according to findings and in the databases. It is noteworthy that all the information was obtained from scientific research databases that were at a high level in terms of credibility and also for the validity of articles obtained from the Internet and various databases was reviewed by the research team. And were selected based on the opinion of the research team and also based on the agreement of the members based on the inclusion criteria. After searching for resources, clinical guides, articles and books were extracted. The texts were studied and the components of the clinical guide to end-of-life care were collected based on the information and categorized according to the conditions of the articles. Draft recommendations were prepared in the form of a questionnaire and general editing was done according to the professors

- Second Stage

Objective 2: To determine the degree of agreement of teachers in the components of clinical guidelines for end-of-life care of children.

Description of Objective 2: The survey was conducted in a group of specialists and professors by round method, in which the group presented its recommendations and after discussion, the desired clinical guide was localized and finalized.

Results of the first stage findings (Objective 1)

Determining the components of the clinical guide for end-of-life care with a family-centered care approach

At this stage, the components of the end-of-life care clinical guide were determined with a family-centered care approach. Therefore, in order to identify different areas of child end-of-life care with a family-centered care approach as well as clinical guides in this field, the researcher decided to identify and extract the necessary databases and information sites in this field. Related to child end-of-life care with a family-centered care approach around the world using related keywords according to findingsin the world's databases. Selected studies from the different countries are according to Table 3.

In scoring the focus group on the recommendations during the death of the child, all the recommendations received an acceptable score in terms of desirability and applicability, except for items No. 4 and 19, which have a low score in terms of desirability and applicability.

Discussion

After extracting the recommendations, they were classified into three areas of pre-mortem care, infant mortality care and post-mortem care. Bennett was family-centered (16).The analysis of research findings at this stage led to the preparation of end-of-life care components for children with a family-centered care approach and its initial draft in the form of a questionnaire (17). In compiling the initial draft of the clinical guide to end-of-life of children with a family-centered care approach in the form of a questionnaire, clinical guidelines and related articles described.

After analyzing the questionnaires and determining the priority and applicability and level of items, the items that had priority and applicability of more than 3 as well as the items that had low level were identified to be discussed in the focus group. And the necessary corrections should be made that the grade of items A, B, C, D according to the localized clinical guide of female urinary incontinence, which was compiled by the Center for Management of Uroganological Knowledge of Tabriz University in August 2013, and with this guide Su is (Center for Management of Uroganology Knowledge, Tabriz University of Medical Sciences, 2013).

Items related to care during infant mortality were more accepted than pre-mortem and post-mortem care, which are the reasons for the lack of nursing staff, high workload, and lack of time. Also, due to entering the critical phase due to the imminent death of the child at this stage and the need for direct intervention of nurses in order to provide care services for the child, control the environment and have direct interaction with the family, recommendations related to the acceptability stage and more priority Had in their view. End-of-life care requires a medical team, and all people involved in child care are team members, including doctors, nurses, parents, and religious counselors.

It turned out that the person in charge and performer of most of the care was the nurse, which explains the fact that more nurses than other team members and that nurses spend most of their time with the patient. The team is led by a doctor and supports the child and family is also in charge. Nurses have a role of support, education and direct care of the child in this regard. In addition, they should improve their performance and by combining knowledge and skills to expand the comfort of the child and family during the later stages of life. Religious counselor meets cultural, religious and social needs.

As the findings of the first phase of the research are presented in the tables, there was some ambiguity among some experts regarding these items, which were among the items discussed in the focus group. Also, the findings of the second phase of the research in the tables of recommendations that had a low score in terms of rank and applicability or a low level of recommendations were also among the items discussed in the focus group.

The group was asked to present their ideas according to local conditions and cultural contexts, community beliefs and current laws. The results of the analysis of the findings of the first and second stages of the study of the title of the findings related to the focus group, the reason for the entry of the item into the discussion and the result mentioned and the cases that were discussed more and the result of the discussion are as follows:

In scoring the recommendations before the death of the child, the item "Establishing the possibility of the presence of the child's sister, brother or classmate at his bedside" had a low performance capability, which from the perspective of those present in the focus group, due to national laws to prevent Children under the age of 12 are not allowed to enter hospital wards due to nosocomial infections (18).

On the other hand, the biggest fear of the child at the end of life is separation from parents, sisters, brothers and classmates (friends) who, if possible, their presence at the patient's bedside helps to provide psychological support to the child. According to a study conducted by Perrin and Shipman on the presence of teachers and classmates at the bedside of a hospitalized child in the later stages of life, the results showed that their presence on the bedside of the child reduces the child's anxiety accepting this item the focus group agreed (19).

The social worker meets financial and welfare needs. The psychologist supports the spiritual and psychological needs. Parents are a constant phenomenon in child care and throughout the end-of-life care period of the child, the health care system provides an opportunity for the treatment team to improve family-centered care by developing partnerships and collaborations with parents (20).

Clearly, end-of-life child care affects the quality of life and functioning of the family and other family-related systems (2).The quality of life of the child in the later stages of life is closely related to nursing care, because nursing care not only improves the quality of life of the child but also significantly improves the performance of parents and their role for other family members (21).

Then, these items were compiled as clinical guidelines. In this study, guides and articles in scientific databases that were closer to the research topic were used for the clinical guideline components of the model framework. In this regard, several studies were in line with our research process.

Conclusion

In this study, a comparative research method with a localization approach was used to develop a clinical guide for end-of-life care of children with a family-centered care approach. The review of studies was based on an evidence-based process, which was one of the limitations of the study. In the next step, a focus group of experts was formed and then the recommendations were modified based on the Delphi technique. In the group of experts, its scientific validity was confirmed using the opinions of experts, and the components of end-of-life care of children were determined with a family-centered care approach to develop a clinical guide. In this regard, several studies were in line with our research process.

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Tables

Table 1. Number and percentage of studies in different countries

Percentage of studies	Number of studies	Country
4%	2	Iran
34%	17	America
18%	9	Australia
10%	5	England
2%	1	Russia
24%	12	Canada
4%	2	Brazil
4%	2	Germany

Table 2. End-of-life care, pre-mortem care

Applicability	Desirability	Level of evidence	reference	Items
2	7	A	(Guidline to End of Life Care,2012)	Inform the family about the child's condition (course of the disease) in a simple and completely honest way
		A	(Guidelines for end-of-life care and decision-making,2005)	
1	9	A	(Guidline to End of Life Care,2012)	Provide adequate hydration for the child with minimal aggressive measures
		C	(Bogetz et al , 2014)	
1	8	C	(Hawryluck et al , 2013)	Maintain a quiet environment and reduce noise in the ward
		C	(Sturman & Cassidy, 2010)	
1	8	A	(Guidelines for end-of-life care and decision-making,2005)	Develop an end-of-life clinical care plan for the child according to the disease process, the child's condition, and the facilities available
		C	(Morell et al , 2011)	
		C	(Ranse et al , 2012)	
2	9	A	(Guidelines for end-of-life care and decision-making,2005	Avoid doing unnecessary aggressive actions for the child
		C	(Schwantes et al , 2014)	
3	6	C	(Machajewski & Kronk , 2013)	Facilitate the presence of a child's sister, brother or classmate at his or her bedside

Table 3. End-of-life care, child death care

Final revised recommendations	Suggested recommendations	
Provide adequate hydration for the child by applying minimal aggressive treatment measures	Provide adequate hydration for the child by applying minimal aggressive treatment measures	Provide adequate hydration for the child by applying minimally invasive procedures
Focus group discussion	Who should answer the family's questions about the child's condition at the end of life?	Inform the family about the child's condition (course of the disease) in a simple and completely honest way
Avoid unnecessary aggressive treatment for the child	Avoid unnecessary aggressive treatment for the child	Avoid unnecessary invasive procedures for the child
Maintain a quiet environment and reduce noise in the ward	Maintain a quiet environment and reduce noise in the ward	Provide a quiet environment and reduce noise in the ward

Table 4. End-of-life care, post-mortem care

Applicability	Desirability	Level of evidence	reference	Items	Row
A) End-of-life care during the death of a child					
2	8	A A C	(Guidline to End of Life Care,2012) Guidelines for end-of-life care and decision-making,2005) (Tomlinson et al , 2010)	Pay attention to the religious beliefs and beliefs of the family around the time of the child's death (reading prayers, lighting candles, reading the child's favorite book)	1
2	8	A C C	Guidline end of life care for infants, children and young people ,2014 (Lotstein,2010) (Brendel et al , 2010)	Turning parents' attention to caring for healthy children (reducing the deprivation of healthy siblings of regular parental attention and care)	2
2	8	A C C	(Guidline to End of Life Care,2012) (Becker et al , 2013) (O'Gorman , 2010)	Encourage families to meet and consult with trusted religious and cultural figures (or the hospital's clergy and family counselor)	3
1	9	A C C	(Guidline to End of Life Care,2012) (Lustbader, 2013) (Pituch et al , 2011)	Providing a favorable environment for the death of the child (adequate level of light, proper ventilation, privacy of the child and family)	4
3	6	A C C	)Guidline end of life care for infants, children and young people ,2014 (Ranse et al, 2014) (McGuire et al , 2012)	Holding a joint meeting regarding the decision not to perform resuscitation and care based on providing comfort to the child and family (meeting with the presence of the doctor and the responsible nurse and the child's family)	5
1	8	A C	(Guidline to End of Life Care,2012) (Pelant et al , 2012)	Allow the child to express his or her fears and worries about death, such as expressing the child's fears that he or she will leave family and friends.	6