

An Investigation to the Palliative Care Requirements in Neonatal Intensive Care Units from the Perspective of Care Providers

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ABSTRACT

Background: The need for palliative care has been realized for decades. To establish such a system in Iran, proper investigation and grounding of administration requirements are necessary.

Aim: To determine the current requirements for implementing this program at the level of neonatal intensive care units in selected hospitals affiliated to Shahid Beheshti University of Medical Sciences.

Methods: In this study, a questionnaire was completed to assess the implementation requirements of palliative care program and standards in the neonatal intensive care units at three levels of family-related factors, managerial factors and human resources. Then, the data were analyzed using descriptive statistics in SPSS v21.0.

Results: The results showed that in Mofid and Mahdih hospitals, proper implementation of this program requires improvements in family-related factors, but in the case of human resources and management factors, there is no need to implement this program. Based on the scores obtained in Imam Hussein Hospital, the required backgrounds to implement this program were absent in all three dimensions.

Conclusion: In order to implement the palliative care program in neonatal intensive care units in the hospitals affiliated to Shahid Beheshti University, it is necessary to prepare the preliminary arrangements regarding both human and managerial factors, and to improve the existing conditions in the family-related factors.

Keywords: palliative care, implementation requirements, care providers

INTRODUCTION

Health is a fundamental right and requirement of every human being, to the extent that the development of communities can be judged from their health quality (Peterson Flieger et al., 2018). Thus, it is required for healthcare providers to support the people for living healthier (Danielson 2019). In its 2030 Agenda, the World Health Organization (WHO) has included "the healthy lives and promote well-being for all at all ages" as one of the programs for sustainable development of countries (R. Connor, 2018). According to the WHO definition, health refers to a state of complete physical, mental and social well-being even in the presence of diseases and there is no merely need the absence of disease to confirm this definition (Callahan, 2009). Thus, health should be perceived even beyond the absence of disease and infirmities and biophysical parameters (WEAVER et al., 2014; Mirkarimi et al., 2018).

However, the right to health is a fundamental right of every human being that is respected in many international human rights laws, and supportive and palliative care is also recognized as part of the health system (Harding et al., 2008). According to the definition of health, supportive and palliative care systems are established primarily to maintain health, and their main purposes are to improve the quality of life in patients, enhance the quality of death in patients, and support patients' families (Shadpour, 2006; Rassouli et al., 2017). The availability of palliative care to all members of a community requires its public implementation in the treatment system. In May 2014, the

World Health Assembly adopted a resolution on the full implementation of palliative care in the field of health care (World Health Organization, 2014).

WHO also supports the concept of end-of-life care and the pain management model for achieving the best quality of life for infants in the neonatal intensive care units (Carter, 2018). Accordingly, the 2002 Cape Town Palliative Care Declaration has recognized the palliative care as a right for all adults and children with life-limiting illnesses (Mpanga Sebuyira et al., 2003), and governments should recognize the access to palliative care as a human right (Rassouli et al., 2017).

Thus, the application of palliative care has been increasingly considered in recent years as end-of-life care for parents and infants diagnosed with an incurable and life-limiting disease (Cummings J et al., 2015). Using a multipurpose approach at different social, cultural, economic and psychological levels at the hospital, community and home, this type of care begins at diagnosis stage (Klick and Hauer 2010; Catlin et al., 2015; National Association of Neonatal Nurses Position Statement, 2016; World Health Organization, 2016a,) and continues until death and even until the end of the mourning and the return of the family to the normal life (World Health Organization, 2019).

A review of the mortality rate of infants reveals the importance of implementing such a program. Yearly about 2,500 deaths of infants and children are documented in hospitals, 86% of which occur in the neonatal or pediatric intensive care units, of which about 70% (15,050 deaths) in the neonatal age range (World Health Organization,

2016). According to the National Organization for Civil Registration in 2015 and the first half of 2016, the mortality rate of infants is 12 per thousand live births, which is significant and reveals the need for palliative care in a large number of infants and their families (Organization ICR, 2017).

Although the concept of palliative care has been introduced in the neonates (Kain et al., 2009) and recently applied to the neonatal population (Al-Alaiyan and Al-Hazzani 2009), it has not been implemented in the neonatal ward in a comprehensive, continuous and integrated manner (Romesberg 2007). Because providing palliative care for infants with life-limiting conditions in the later stages of life is considered as a challenging decision in terms of moral, legal and clinical concepts, and detailed information on the implementation requirements of this program is not yet available (de Rooy et al., 2012).

There is little research on the basics and requirements of palliative care interventions in the prenatal and neonatal stages (Balaguer et al., 2012), thus, recognition of the requirements of the treatment system is essential to provide palliative care for infants (Kilcullen and Ireland 2017).

The examination of the requirements of a system could determine its value and foundation and whether a given program should be implemented (Salsali et al., 2009). Since the implementation of palliative care in the neonatal intensive care units is challenging, it is necessary to prepare the implementation requirements of such a program in three areas related to parents, health care providers and management system (Salmani et al., 2018).

Studies conducted in Iran show that the existing knowledge toward palliative care is not well defined and has not been seriously included in the medical sciences curricula. Moreover, the small number of studies on the concept of palliative care and its requirements has limited the application of this concept in research, so that related studies are very limited in Iran. In addition to developing knowledge, various studies on the palliative care and its requirements can, in fact, pave the way for providing palliative care in the cultural context of our society by interpreting the views of nurses and physicians and addressing the involved factors as well as reviewing studies conducted in this field and in the others (Mardani Hamule et al., 2014).

Successful implementation of any program requires to identify and provide a suitable platform and the lack of a suitable platform can lead to program failure. This platform consists of implementation requirements, i.e. the rules, regulations and infrastructure required to implement and launch a program. In the treatment sector, on the other hand, there is an urgent need to expand palliative care centers. Thus, one of the demands of this sector is to recognize the appropriate strategy to achieve the best results, including comprehensive care for sick infants, increasing family satisfaction, improving the ability of neonatal disease diagnosis and prognosis, increase symptom management, reduce the use of human resources and ultimately, reduce the loss of financial resources and cost-effectiveness of services (Shirinabadi Farahani et al., 2018) (Hasan et al., 2017). Studies conducted on the existing requirements and contexts also

indicate the importance of this issue, as the study by Zargham et al. (2015) identified the pros and cons of the palliative care program implementation from the perspective of nurses and stated that ignoring this urgent need is a factor that can lead to failure in full implementation of the program. Azizzadeh Forouzi (2017), on the other hand, pointed out that almost 43.63% of nurses are opposed to the implementation of this plan because they believed that the structure and requirements needed to establish this plan are absent. Moreover, Salmani et al. (2017) also indicated that all the obstacles mentioned in the articles can be classified into three domains related to parents, medical staff and the care system, and it is essential reviewing them. As a result, the researchers tried to study the implementation requirements of palliative care program from the perspective of care providers in neonatal intensive care units to facilitate the best implementation of palliative care in infants in need.

METHODS

This descriptive study was conducted in the neonatal intensive care units of selected hospitals affiliated to Shahid Beheshti University of Medical Sciences in 2018 with the aim of examining the requirements of palliative care program from the perspective of care providers. The research population includes all care providers in the neonatal intensive care units, which due to the limitation of research units, complete enumeration method was applied to calculate the number of samples.

Data was collected using completion of a researcher-made questionnaire designed based on an extensive review of literature and the existing article on difficulties of palliative care implementation (Ms. Salmani's article) which consisted a total of 101 items in three dimensions including family (43 items), human resources (31 items) and managerial (27 items) factors. The questionnaire was designed as a 5-point Likert scale (strongly agree, agree, neutral, disagree, and strongly disagree). The minimum score in each of the dimensions was zero, and the maximum scores obtained for family, human resources and managerial dimensions were 172, 124 and 108, respectively. A higher score in a dimension indicates the more complete requirements for implementing palliative care in that dimension from the caregivers' perspective. A 71-100% compliance from the perspective of care providers indicates a suitable ground for the implementation of palliative care program, 40-70% indicates the need for improving conditions and eliminating the existing weakness, and a compliance of less than 39% indicates the lack of necessary conditions for the establishment of the program.

The validity of the questionnaire was determined using content validity ratio and the face validity methods. In order to evaluate the validity, the questionnaire was reviewed by ten experts in the field of nursing, palliative care and instrumentation, and the necessary changes were applied after collecting their opinions on clarity and simplicity of the questionnaire. The collected responses were calculated based on the CVR formula. The CVR score of each 101 items was greater than the values in the Lawshet table (0.79). The reliability of the instrument was

examined using the internal consistency reliability method (calculating Cronbach's alpha). After the instrument was completed by 15 people of the statistical sample, Cronbach's alpha was calculated to be 0.9. Finally, the stability reliability was evaluated through re-evaluation and comparison of results; for this purpose, the questionnaires were completed by 15 people selected through random sampling, and completed again by them two weeks later. Accordingly, the stability reliability was determined by calculating the intra-class correlation coefficient (ICC) of 0.92.

The collected data were analyzed using descriptive statistics including frequency distribution table, percentage, central and dispersion indices. Chi-square test was used to examine the relationship between the obtained scores and demographic variables. To analyze the nonparametric data, Mann-Whitney U, Kruskal-Wallis and Spearman correlation tests were used, respectively. Finally, regression and ANOVA were used to examine the simultaneous effect of demographic variables. A significance level of 0.05 was considered in the tests.

After permission was obtained from the relevant authorities of the abovementioned hospitals and nursing units, the questionnaires were answered by the nursing staff for three months from the beginning of November 2015 to the end of January 2016 in three shifts of morning, evening and night, and then were collected on a certain day.

RESULTS

The purpose of this study was to identify the requirements of palliative care program in neonatal intensive care units in selected hospitals affiliated to the Shahid eheshti University of Medical Sciences from the perspective of caregivers. To evaluate the results, the scores obtained from different fields in three hospitals A, B and C were first evaluated on a scale of 100 to be compared with the existing evaluation

criteria. Some demographic information is provided in Table 1.

The perspectives of care providers on palliative care requirements are examined in three dimensions including family-related factors, managerial factors, and human resources-related factors.

In this study, the data related to all three hospitals is analyzed in general. Although the difference in mean scores is generally significant in all three domains, the score obtained for family-related factors is higher than the other domains followed by human resources and managerial factors, respectively. In other words, the family-related factor is, in general, the most effective requirement in providing palliative care from the perspective of care providers. Table 2 shows the information of these areas and the related scores. Comparison of the scores obtained for the dimensions of palliative care requirements from the perspective of care providers in each hospital is also reported in Table 3.

According to the Table 3, the results of ANOVA test to compare the dimensions of palliative care requirements in Hospital C show that there is a significant difference between the scores obtained for all three dimensions. The score obtained for family-related factors is significantly higher than the other domains followed by human resources and managerial factors, respectively. In the hospital B, however, the difference in scores of family-related factors is significant with other dimensions, but there is no significant difference between the scores obtained for human resources and managerial factors. The difference between the scores of family-related factors and managerial factors is significant in hospital A, however, there is no such a significant difference between the scores obtained for other dimensions.

Table 1: Some demographics of the staff of neonatal intensive care units in hospitals A, B and C

Hospital	No. of active beds	No. of nurses per shift	Level of Education	Gender
A	21	First shift : 9	BSc : 30	Female : 35
		Afternoon shift : 7	MSc : 5	Male : 0
		Night shift : 7	PHD : 0	
B	70	First shift : 20	BSc : 56	Female : 60
		Afternoon shift : 18	MSc : 4	Male : 0
		Night shift : 18	PHD : 0	
C	12	First shift : 7	BSc : 28	Female : 30
		Afternoon shift : 4	MSc : 2	Male : 0
		Night shift : 4	PHD : 0	

Table 2: Comparison of different dimensions of palliative care requirements from the perspective of care providers in all three hospitals

No.	Dimension	Mean and standard deviation	One-way ANOVA test	Tukey multiple test results
1	Family-related factors	1.66 ± 0.34	F = 39.737 P < 0.001 Df = 2	Family-related factors vs Human resources (P < 0.001)
2	Human resources	1.41 ± 0.421	F = 39.737 P < 0.001 Df = 2	Family-related vs managerial factors (P < 0.001)
3	Managerial factors	1.18 ± 0.405	F = 39.737 P < 0.001 Df = 2	Human resources vs managerial factors (P < 0.001)

Table 3: Comparison of the scores obtained for dimensions of palliative care requirements from the perspective of care providers in hospitals

No.	Dimension	Hospital	Mean and standard deviation	One-way ANOWA test	Tukey multiple test results
1	Family-related factors	B	1.72 ± 0.292	F = 18.438 P < 0.001 Df = 2	Family-related factors vs Human resources (P < 0.001)
		A	1.59 ± 0.502	F = 5.04 P = 0.008 Df = 2	Family-related factors vs Human resources (P = 0.55)
		C	1.69 ± 0.25	F = 26.065 P < 0.001 Df = 2	Family-related factors vs Human resources (P < 0.001)
2	Human resources	B	1.37 ± 0.392	F = 18.438 P < 0.001 Df = 2	Family-related vs managerial factors (P < 0.001)
		A	1.44 ± 0.586	F = 5.04 P = 0.008 Df = 2	Family-related vs managerial factors (P = 0.006)
		C	1.42 ± 0.293	F = 26.065 P < 0.001 Df = 2	Family-related vs managerial factors (P < 0.001)
3	Managerial factors	B	1.19 ± 0.34	F = 18.438 P < 0.001 Df = 2	Human resources vs managerial factors (P = 0.116)
		A	1.14 ± 0.584	F = 5.04 P = 0.008 Df = 2	Human resources vs managerial factors (P = 0.100)
		C	1.21 ± 0.291	F = 26.065 P < 0.001 Df = 2	Human resources vs managerial factors (P = 0.006)

DISCUSSION

In this study, the requirements of implementing palliative care program in neonatal intensive care units are investigated in selected hospitals in three dimensions of family-related factors, human resources and managerial factors. According to the results of this study, care providers identified the family-related factors as the most necessary dimension in the implementation of palliative care in the neonatal intensive care units.

There are some studies examined the impact of family-related factors on the success or failure of palliative care. For example, in a study conducted by Nielsen et al. (2019) in the United States, the effective factors in providing high quality palliative care identified by patients' families were: clinical decision-making based on patient desire, patient comfort, patient privacy, patient access to family and particularly family support during illness (Nielsen et al., 2019). In another study by Strandas et al. (2018), they concluded that pursuing a family-centered care program and mutual trust between family and medical staff are two important factors in palliative care that can help the nurse and patient in achieving their treatment goals. Such a mutual relationship can improve the physical and emotional well-being of patients, facilitate the adaptation to their illness, reduce pain and provide them to a better experience of death, and prove nurses with a greater professional satisfaction. As a result, therapeutic relationships between nurses and patients' families can facilitate the implementation of palliative care program, and therefore, constant review of the relationship is necessary for improving the quality of palliative care (Strandas and Bondas 2018) (Soltany et al., 2020).

Moreover, De Graaff et al. (2012) conducted a content analysis in Turkey and stated that health care providers identified the family-centered care program as a key factor to facilitate the provision of palliative care. They further argued that family-centered care is currently provided in the right range, however, providing palliative care services with higher qualities requires further development and training in this area (DE GRAAFF et al., 2012). On the other hand, in a study conducted by Taleghani et al. (2018) on family-related factors, nurses involved in the study stated that focusing only on family-related factors in implementing palliative care programs exacerbates physical and mental fatigue in staff and may hinder the successful implementation of this plan. The nurses believed that the difficulty of being with the family and the feeling of physical and mental fatigue are two hindrances in providing palliative care, and that family-related factors prevent the implementation and provision of palliative care (Taleghani et al., 2018). (Soltany, 2016)

The results of the present study showed that care providers identified the human resources as the second important factor in examining the requirements of palliative care. Human resources-related factors are effective in the success or failure of palliative care program. The results of a study by Mandey et al. showed that the provision of palliative care is influenced by a wide range of organizational and professional factors identified as implementation requirements; In order to facilitate the provision of palliative care, it is also recommended to improve the quality of human resources performance, inter-professional communication and assistance. In addition, the facilitating role of home caregivers on the provision of

palliative care is also emphasized (Denney-Koelsch et al., 2016). (Soltany, 2020)

Junger, Pastrana, Pestinger, Kern, Zernikow, Radbruch (2002) conducted a content analysis in the Netherlands and stated that the concept of palliative care from the perspective of nurses generally includes efforts toward establishing a purposeful approach of caring and increasing the sense of well-being in patients. Also, the nurses believed that the nature of their role in palliative care is formed according to the context of their work environment. In other words, the role of human resources, the number of skilled human resources and the quality of their performance are important factors that must be considered while the provision of palliative care. In this regard, they further stated that better implementation of this program requires the improvements in the conditions which currently is not favorable.

A 2016 study in the UK found that palliative care processes depended on the effectiveness of professional relationships. The nurses studied in another research mentioned the individual attitudes toward work, job satisfaction, job stress, coping strategies, and personal and professional issues as facilitating factors in the provision of palliative care of patients. The results of this study indicated that job stress, job satisfaction and individual attitudes are barriers to the implementation of this program, and that the better implementation of this program requires plans to control job stress and increase job satisfaction and improve individual attitudes toward the program, because the necessary infrastructure to run this program is not currently available (Wiechula et al., 2016).

Quantitative findings of Kyc et al. (2019) study on the requirements of the palliative care program for adults showed that medical staff's knowledge of the value of palliative care leads to professional commitments and facilitating the comprehensive palliative care services in the form of social care systems, and thus the human factor plays a major role (Kyc et al., 2019).

The results showed that managerial factors are the third important requirement of palliative care program from the perspective of care providers. Mandey et al. studied the role of managerial factor in providing effective palliative care and argued that inter-professional cooperation may play a major role in providing palliative care due to its multi-professional nature, and this cooperation is possible via hospital management supervision. However, the role of this factor was less than the others in our study, which indicates the lack of a management plan toward establishment of inter-professional collaboration to provide high quality palliative care.

Junger, Pastrana, Pestinger et al. (2010) cited the possible barriers in palliative care implementation from the perspective of related experts, including a lack of clear financial and legal regulations, gaps in care provision, and access to the services. They also stated that successful implementation of such a program would not be possible in the absence of a proper managerial infrastructure. According to the results, it can be said that this study is in line with our findings on managerial factors, and both studies concluded that weaknesses in managerial factors can lead to a failure in the implementation of the program. The results of another study in Germany about the program

implementation objectives at the managerial level reported the lack of transparency of responsibilities among health care staff and other stakeholders as well as insufficient financial resources as two important factors with negative effects on providing palliative care services. The authors of this study declared that insufficient financial resources allocated to personnel insurance and salaries, and to procurement of necessary equipment has led to problems in the program implementation process. On the other hand, the uncertainty in the executive responsibility of among medical staff leads to confusion in the implementation of their responsibility and causes a conflict of role between the medical staff which, in turn, leads to failure in the implementation of this type of care (Strandas and Bondas 2018) (Ghods et al., 2017)

CONCLUSION AND RECOMMENDATIONS

Studies have shown that palliative care is a multi-dimensional concept that can be defined from different perspectives. A review of literature on the concept of palliative care showed that this concept not only focuses on the patient and maintaining his/her independence, but also supports the patient's family. Palliative care services are also influenced by some organizational factors such as human resources and professional issues, as well as management and managerial function. Considering the importance of palliative care in the nursing profession, on one hand, and the lack of qualitative and quantitative research in this field in the country, more extensive research is required to clarify the mental complexities in this concept and to provide high quality palliative care.

Given the limitations of the studied hospitals, it is suggested that the study be conducted in a wider area and in other cities, so that more reliable results can be presented to the treatment system and the authorities. It is also suggested that a similar study be conducted on other staff in the health care system, including physicians, hospital officials, and even at the macro level to examine the requirements and barriers to the implementation of palliative care program to determine the existing and desired conditions and draw a better roadmap.

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