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Perspective of Mothers of Children with Malignancies of the Quality of Palliative Care

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Abstract

This study aims to (1) identify the factors that can predict the quality of palliative care, (2) investigate the differences in the quality of palliative care between the groups of child's gender and mothers' level of education. A descriptive predictive correlational design was used to guide this study which was conducted in The Pediatric Welfare Teaching Hospital and Child's Central Teaching Hospital, Baghdad City. The study included a convenience sample of 165 mothers of children with malignancies. The study instrument encompasses The Perspective of the Quality of Palliative Care Scale. The study results display that palliative care is good from the perspectives of most mothers.

There are statistically significant differences in the dimensions of caregiver's listening skills;

psychosocial and spiritual dimensions, and overall palliative care between child's gender groups.

There is a statistically significant difference in the psychosocial and spiritual dimensions among mothers' level of education groups. Additionally, mothers of female children seem seek more palliative care pertinent to listening skills, psychosocial dimension, and overall palliative care. The student researcher recommends that there is a pressing need by the Iraqi Ministry of Health to devote greater health efforts with the goal developing the palliative care, particularly in the critical care units in pediatric hospitals.

Keywords: *Perspective of Mothers, Children with Malignancies, Quality of Palliative Care.*

Introduction

Cancer is an uncommon illness that necessitates special care for the children and family from the moment of diagnosis. It is a leading cause of death worldwide which the mortality rate of children with cancer has dropped by over half (Nauck, Alt-Epping and Benze, 2015).

Cancer is an uncommon illness that necessitates special care for the patients and family from the moment of diagnosis. It is a leading cause of death worldwide. Thus, it causes great anxiety and concern in many people. Nearly one in four deaths in the United States are caused by it, making it the second most prevalent killer behind heart disease. According to predictions, 35% of cancer patients would die in 2013 and 65% will still be surviving (Alt-Epping & Nauck, 2015).

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Patients with cancer experience unique physical, psychological, social, and spiritual requirements during treatment that call for a multifaceted strategy to address them. Even among those who are cured, a large number have a variety of incapacitating disease- and treatment-related symptoms that can be very upsetting and compromising to their quality of life (American Cancer Society, 2023).

Around the world, children die every day. They die from a number of conditions, including cancer, acquired immunodeficiency syndrome (AIDS), accidents, birth problems, and undernourishment. No of the circumstances or causes, the loss of a child causes families and communities nothing but anguish, sadness, and suffering. However, there is a group of specialists whose main responsibility it is to lessen the suffering of these youngsters as they approach death and to help mourning family members. Around the world, countless medical professionals, nurses, social workers, psychiatrists, and advocates devote their lives to ensuring that kids and families get the best treatment possible in these challenging situations. These dedicated professionals, who come from many fields, have discovered a common ground in the area of pediatric palliative care. Pediatric palliative care, which emerged from the modern hospice movement of the 1960s, aims to provide children with comprehensive care for children in a holistic manner (Knapp et al., 2012).

Palliative care is therefore distinctive in the field of healthcare, particularly pediatric palliative care disease (Knapp & Thompson, 2012). Pediatric acute and chronic pain management alternatives are constantly being studied, and new technologies and delivery methods are becoming accessible every day (Tobias et al., 2014)). The child may experience disability, physical pain, and other uncomfortable sensations as a result of the disease and treatments, severe alterations in their social world, and disruption of their developmental process (Pinheiro et al., 2012).

Palliative care in all its guises is built upon the premise of holistic care. A defining feature of palliative care, however, is its attention to spiritual care and spirituality, which is paramount for individuals as they face advancing disease and their passing and that of their families as they anticipate their loss (Radbruch et al., 2020).

Involving families in supporting and caring for their children who need palliative care is a necessity of good practice. Although serious illness can impact autonomy, some conditions that are both life-threatening and life-limiting do not impact cognition and related capacity until the end of life.

While parents and siblings should be involved when making decisions for children and younger adolescents, friends and significant others may take precedence for older adolescents It can be challenging to strike a balance between the needs and preferences of all family members, but treating the young person equally and giving them the guidance or support they need to make their own decisions fosters independence, self-confidence, and a sense of self (DeCourcey et al., 2020).

This study aims to (1) identify the factors that can predict the quality of palliative care, (2) investigate the differences in the quality of palliative care between the groups of child's gender and mothers' level of education.

Methodology

Study Design

This study was based on a descriptive predictive correlational design. In order to anticipate the value of one of the variables depending on the value of the other variable(s), the predictive correlational design is used to identify the strength and direction of correlations between or among variables.

Study Setting

This study was conducted in each of Pediatric Welfare Teaching Hospital – Medical City Complex and Child's Central Teaching Hospital – Al-Karkh Health Directorate, Baghdad City.

Study Sample

The study included a convenience sample of 165 mothers of children with malignancies. The

desired sample size is achieved by researchers adding available subjects to the study. There are several options for choosing a convenience sample. The final sample size is 165.

Study Instrument

The study instrument encompasses mothers' sociodemographic characteristics of age, level of

education. It also includes children's sociodemographic characteristics of age and gender. It also includes children's diagnoses, children's medical profile (duration of diagnosis, hospitalization duration). It also includes the modified version of the 'Patients' Perspective of the Quality of Palliative Care Scale (Kolagari et al., 2022) which measures determine the quality of the palliative care given to patients.

Data Collection

Data were collected through structured interviews with the study participants for the period from December 2nd, 2022 to January 31st, 2023. Structured interviews are verbal exchanges with participants that provide the researcher with increasing levels of control over the interview's content with the aim of gathering crucial information.

Statistical Analyses

The data were analyzed using IBM's statistical package for social sciences (SPSS), version 27. Frequency and percentage descriptive statistical measures were applied.

Ethical Considerations

The student researcher addressed study details with representatives from the Pediatric Welfare Teaching Hospital after gaining approval from the College of Nursing, University of Baghdad, for the study – Medical City Complex and Child's Central Teaching Hospital – Medical City Health Directorate, Baghdad City.

Results:

Table 1. Participants' sociodemographic characteristics (N = 150)

Variable	Class	Frequency	Percent
Mothers' Age (Years) Mean (SD): 34.30 ± 10.61			
Level of education	Read and write	40	26.7
	Elementary school graduate	56	37.3
	Middle school graduate	24	16.0
	High school graduate	14	9.3
	Associate degree	5	3.3
	Bachelor's degree	11	7.3

SD: Standard deviation

The study results reveal that the mothers' mean age is 34.30 ± 10.61.

Concerning mothers' level of education, less than two-fifth are elementary school graduates (n = 56; 37.3%), followed by those who read and write (n = 40; 26.7%), those who are middle school graduate (n = 24; 16.0%), those who are high school graduate (n = 14; 9.3%), those who hold a bachelor's degree (n = 11; 7.3%), and those who hold an associate degree (n = 5; 3.3%).

Table 2 Linear regression analysis for the factors predicting palliative care

		t-test for Equality of Means				
	F	t	df	p-value	Mean Difference	Std. Error Difference
Availability of caregivers	.407	-.271	148	.786	-.14535	.53563
Serenity	1.146	-1.708	148	.090	-.54942	.32166
Information	2.515	-.777	148	.439	-.25763	.33168
Pain management	.349	-.548	148	.584	-.09775	.17834
Caregiver's listening skills	10.283	-2.215	148	.028	-.86955	.39265
Psychosocial and spiritual	.367	-2.996	148	.003	-1.55596	.51933
Respect for the patient	.335	-.881	148	.380	-.56395	.64002
Palliative Care	.397	-2.162	148	.032	-4.03961	1.86850

df = Degree of freedom; F = F-statistics; Sig. = Significance; t = T-Statistics; Std. Error Difference = Standard Error Difference

The study results display that none of the mother's age, child's age, duration of diagnosis, and hospitalization duration could predict the palliative care.

Table 3. Differences in the palliative care domains between the child's gender groups

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Availability of caregivers	Equal variances assumed	.407	.525	-.271	148	.786	-.14535	.53563	-1.20383	.91313
	Equal variances not assumed			-.276	142.713	.783	-.14535	.52734	-1.18776	.89707
Serenity	Equal variances assumed	1.146	.286	-1.708	148	.090	-.54942	.32166	-1.18506	.08622
	Equal variances not assumed			-1.740	143.803	.084	-.54942	.31570	-1.17342	.07459
Information	Equal variances assumed	2.515	.115	-.777	148	.439	-.25763	.33168	-.91308	.39781
	Equal variances not assumed			-.798	146.244	.426	-.25763	.32270	-.89539	.38013
Pain management	Equal variances assumed	.349	.555	-.548	148	.584	-.09775	.17834	-.45017	.25468
	Equal variances not assumed			-.546	134.365	.586	-.09775	.17887	-.45152	.25602
Caregiver's listening skills	Equal variances assumed	10.283	.002	-2.215	148	.028	-.86955	.39265	-1.64547	-.09363
	Equal variances not assumed			-2.331	147.401	.021	-.86955	.37300	-1.60666	-.13244
Psychosocial and spiritual	Equal variances assumed	.367	.545	-2.996	148	.003	-1.55596	.51933	-2.58222	-.52970

dimensions	Equal variances not assumed			-3.025	140.374	.003	-1.55596	.51432	-2.57278	-.53914
Respect for the patient	Equal variances assumed	.335	.563	-.881	148	.380	-.56395	.64002	-1.82871	.70081
	Equal variances not assumed			-.885	137.926	.378	-.56395	.63733	-1.82415	.69624
Palliative Care	Equal variances assumed	.397	.530	-2.162	148	.032	-4.03961	1.86850	-7.73199	-.34723
	Equal variances not assumed			-2.201	143.599	.029	-4.03961	1.83497	-7.66665	-.41257

df = Degree of freedom; F = F-statistics; Sig. = Significance; t = T-Statistics; Std. Error Difference = Standard Error Difference

The study results demonstrate that there are statistically significant differences in the dimensions of caregiver's listening skills; psychosocial and spiritual dimensions, and overall palliative care (p-value = .028, .003, .032) respectively.

Table 4. Difference in the palliative care dimensions among mothers' level of education groups

ANOVA						
		Sum of Squares	df	Mean Square	F	Sig.
Availability of caregivers	Between Groups	37.191	5	7.438	.704	.621
	Within Groups	1521.642	144	10.567		
	Total	1558.833	149			
Serenity3	Between Groups	35.397	5	7.079	1.896	.098
	Within Groups	537.563	144	3.733		
	Total	572.960	149			
Information	Between Groups	14.003	5	2.801	.688	.633
	Within Groups	585.870	144	4.069		
	Total	599.873	149			
Pain management	Between Groups	11.837	5	2.367	2.114	.067
	Within Groups	161.236	144	1.120		
	Total	173.073	149			
Caregiver's listening skills	Between Groups	46.234	5	9.247	1.626	.157
	Within Groups	818.759	144	5.686		
	Total	864.993	149			
Psychosocial and spiritual dimensions	Between Groups	142.419	5	28.484	2.907	.016
	Within Groups	1411.075	144	9.799		
	Total	1553.493	149			
Respect for the patient	Between Groups	83.226	5	16.645	1.113	.356
	Within Groups	2152.968	144	14.951		
	Total	2236.193	149			
Palliative Care	Between Groups	1276.676	5	255.335	2.011	.080
	Within Groups	18281.917	144	126.958		
	Total	19558.593	149			

df = Degree of freedom; F = F-statistics; Sig. = Significance

The study results reveal that there is a statistically significant difference in the Psychosocial and spiritual dimensions among mothers' level of education groups (p-value = .016).

Discussion

This descriptive predictive study aims mainly to identify factors that can predict the quality of palliative care from the perspective of mothers of children with malignancies. Concerning the factors that can predict palliative care, the study results displayed that none of the mother’s age, child’s age, number of children in the family, duration of diagnosis, and hospitalization duration could predict palliative care. This finding implies that palliative care is invariant irrespective of mother’s age, child’s age, number of children in the family, duration of diagnosis, and hospitalization duration. In other words, palliative care would not vary whether the mother of children.

The study results demonstrated that there was a statistically significant difference in the dimension of caregiver’s listening skills between the child’s gender groups. Further group statistics displayed that the value of the dimension of caregiver’s listening skills was greater among mothers of female children. This finding could be explained as that women can be more concerned about their female children in that they think about their likelihood of survival, openness to the surrounding, and whether they can get marry. These issues may propel the mothers to inquire the healthcare professionals about the prognosis of their female children and listen attentively to them with the hope of getting a ray of hope in terms of their children amelioration. Family members stress the significance of having a constant, attentive conversation with the staff that is open to queries and the expressing of needs (Rawlings et al., 2020).

Understanding the needs and values of the child's parents is essential to enhancing palliative care services for children. Psychosocial research is increasingly focusing on parental experiences and views, including grieving, in an effort to more effectively include parents in pediatric end-of-life care and treatment (The Pediatric Palliative and Hospice Care [NHPCO], 2023). Pease and McMillin (2018) stated that ineffective communication is frequently the cause of differences in how the parents and IDCT understand their child's prognosis. Discrepancies are also observed in how each parent perceives the prognosis for their particular child. Due to other obligations, it can be difficult for both parents to continuously be at their child's bedside. For interdisciplinary care team (IDCT) participants, communicating information to just one parent is not a meaningful form of communication. It is unrealistic to suppose one parent will be able to fully and accurately educate their spouse about their child's medical care, prognosis, and end-of-life.

The study results demonstrated that there was a statistically significant difference in the psychosocial and spiritual dimension between the child’s gender groups. Further group statistics displayed that the value of the psychosocial dimension was greater among mothers of female children. In my opinion, this finding could be explained as that women can have greater worry about their female children in that they think about how likely they can survive, how psychosocially well they would be, whether they can cope with their illness, and whether people in the community can alleviate or aggravate their illness.

Good communication between family members and the IDCT "alleviates fears, pain, and suffering, and enables patients and their families to experience a peaceful death," according to research. This, in turn, has been shown to strengthen familial ties and lessen the dying person's feelings of isolation. Research stated that good communication between family members and the IDCT "alleviates fears, pain, and suffering, and enables patients and their families to experience a peaceful death," according to research. This, in turn, has been shown to strengthen familial ties and lessen the dying person's feelings of isolation (Gilad et al., 2020; RB, 2000). This improved level of communication helps to facilitate the creation of a comprehensive plan that is "medically conducive to perceived positive outcomes, as well as concurrent with the patient's and their family's values and wishes." Therefore, it's important to better understand what encourages and discourages parent participation. Parents are susceptible in the hospital setting, as was mentioned. A number of the variables contributing to the communication problems parents may encounter with reference to their IDCT include their lack of knowledge with the hospital, medical protocols, and expectations regarding their child's treatment. The team must openly acknowledge and understand the strains placed by the sickness on the parents and their kid, while also being as transparent and clear as possible, in order to deepen and develop this crucial caring connection. It is crucial to be straightforward and honest about the child's prognosis as well as what the remainder of their sickness might entail.

The study results demonstrated that there was a statistically significant difference in the overall palliative care. between the child’s gender groups. Further group statistics displayed that the value of the overall palliative care was greater among mothers of female children. In my opinion, this finding could be explained as that women of female children may find their path in different aspects of palliative care with the hope of mitigating the virulence of the illness their children experience, particularly female children. Female children are culturally more sensitive than male ones owing to the Eastern culture that deliberately raise females and consider them like the vase that “should never be scratched”.

Regarding the difference in the palliative care dimensions among mothers’ level of education groups, the study results revealed that there was a statistically significant difference in the psychosocial and spiritual dimensions among mothers’ level of education groups. Further post-hoc analysis demonstrated that mothers who hold a bachelor’s degree perceive the psychosocial and spiritual dimensions as the lowest compared to mothers of other levels of education. In my opinion, this finding could be explained as that mothers who hold a bachelor’s degree may be more knowledgeable about palliative care, psychology, and spirituality compared to mothers of other levels of education. Pease and McMillin (2018) stated that although members of the IDCT typically have a common understanding of disease and death, parent populations should never be subjected to generalizations. Although familiarity among team members can occasionally lead to efficiency and cohesion within the team, skipping the required steps to develop a caring relationship with parents increases the danger of unwarranted harm going forward. This is especially important once a patient's illness starts to worsen. Members of the IDCT are "challenged to respond to the pains and fears parents are experiencing," and seek to use communication to battle them. All parties involved in these conversations should be encouraged to speak honestly because, when discussing death openly, the "subject itself becomes less taboo, ultimately leading toward increased parental comfort in having those conversations outside of the hospital and reopening the discussion as more thoughts and questions inevitably emerge" (Balaban, 2000, p. 3). In the end, the most crucial component of starting EOL conversations with parents is being able and willing to listen to what they have to say and being ready for the unpredictable nature of anxiety, emotions, and expectations.

The roles of IDCT participants don't stop with the patient's medical requirements. Team members will be expected to be available for families, even when curative therapy is no longer working, as the culture of medicine shifts more and more toward patient and family-centered care.

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