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Factors Influencing Caring Ability of Family Caregivers of Children with Cancer

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ABSTRACT

Objective(s): This study aimed to investigate factors influencing the caring ability of family caregivers of children with cancer based on caregiver sex, level of education, kinship to the child, and the child's sex.

Methods: A descriptive study was conducted on 200 family caregivers of children with cancer, selected through non-probability (purposive) sampling technique in the Hematology and Oncology Center at Welfare Teaching Hospital from January 2nd, 2024, to March 27th, 2024. Data were collected using "the Caring Ability of Family Caregivers of Patients with Cancer Scale (CAFCPCS). Through a self-report method. Data were analysis using SPSS (version 24), employing descriptive and inferential statistics.

Results: The study showed that there are several factors that affected the caring ability of family caregivers to their children with cancer, including the child's kinship ($p = .037$), education level ($p = .000$), and monthly income ($p = .003$). Additionally, a significant correlation between the sex of caregivers and effective role play ($p = .022$), negative correlation between the education level of caregivers and the total score of caregiving abilities ($p = .006$).

Conclusion: The study concludes that familial relationship, education level, and income significantly affect caregivers' abilities in caring for children with cancer. The sex of caregivers plays a role in their interactions with children with cancer, with mothers having greater knowledge and broader experience in caregiving.

Recommendations: This study recommends that the Ministry of Health should encourage continuous family support, provide educational programs, and financial assistance to improve the abilities of family caregivers in dealing with their children with cancer. Mothers should be supported through women's workshops, and fathers' participation should be encouraged through specialized training programs.

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العوامل المؤثرة على القدرة على تقديم الرعاية من مقدمي الرعاية الأسرية للأطفال المصابين بالسرطان

المستخلص

الهدف: هدفت هذه الدراسة إلى الكشف عن العوامل المؤثرة على قدرة مقدمي الرعاية الأسرية على الرعاية لأطفالهم المصابين بالسرطان بناءً على جنس مقدم الرعاية، ومستوى التعليم، والقرابة بالطفل، وجنس الطفل.

المنهجية: اجريت دراسة وصفية على عينة مكونة من ٢٠٠ مقدم رعاية أسرية للأطفال المصابين بالسرطان , اختيروا بطريقة غير احتمالية (هادفة) للمدة من ٢ كانون الثاني ٢٠٢٤ إلى ٢٧ أذار ٢٠٢٤ في مركز امراض الدم والاورام في مستشفى حماية الأطفال التعليمي. تم جمع البيانات باستخدام مقياس قدرة مقدمي الرعاية الأسرية للمرضى المصابين بالسرطان, من خلال طريقة التقرير الذاتي. تمت تحليل البيانات بواسطة الحقيبة الإحصائية إصدار ٢٤ باستخدام الإحصاء الوصفي والاستدلالي

النتائج: أظهرت الدراسة بان هناك عدة عوامل اثرت على قدرة مقدمي الرعاية الاسرية على رعاية أطفالهم المصابين بالسرطان منها القرابة للطفل ($p = 0.037$)، ومستوى التعليم ($p = 0.000$)، والدخل الشهري ($p = 0.003$). بالإضافة إلى ذلك،هناك علاقة ذات دلالة إحصائية بين جنس مقدمي الرعاية ولعب الأدوار الفعالة لتقديم الرعاية ($p = 0.022$)، وارتباط سلبي بين المستوى التعليمي لمقدمي الرعاية والنتيجة الإجمالية لقدرات تقديم الرعاية ($p = 0.006$).

الاستنتاجات: استنتجت الدراسة أن العلاقة الأسرية ومستوى التعليم والدخل تؤثر بشكل كبير على قدرات مقدمي الرعاية في رعاية الأطفال المصابين بالسرطان. يلعب جنس مقدمي الرعاية دورًا في تفاعلاتهم مع أطفالهم المصابين بالسرطان، حيث تتمتع الأمهات بدراية أكبر وخبرة أوسع في تقديم الرعاية.

التوصيات: توصي هذه الدراسة وزارة الصحة بالتشجيع على الدعم الأسري المستمر، وتقديم البرامج التعليمية، والمساعدة المالية لتحسين قدرات مقدمي الرعاية الأسرية في التعامل مع أطفالهم المصابين بالسرطان. ينبغي دعم الأمهات من خلال ورش عمل نسائية، وتشجيع مشاركة الآباء عبر برامج تدريبية متخصصة.

الكلمات المفتاحية: مقدمو الرعاية الأسرية؛ القدرة على الرعاية؛ السرطان؛ الأطفال؛ العوامل المؤثرة، الممرضين.

Introduction

Cancer in childhood remains the primary cause of sickness and mortality for children under the age of 15[1]. According to estimates, there are approximately 6 to 7 million cases of childhood cancer globally between (2015-2030) [2].

The primary treatment option for childhood cancer, often combined with surgery, radiotherapy, immunotherapy, hormonal therapy, complementary therapy, and targeted therapy [3]. However, side effects can occur and persist for months or even years following the treatment's completion especially, chemotherapy [4]. Children undergoing chemotherapy may experience a wide range of complications, including fatigue, weakness, nausea, vomiting, pain, diarrhea or constipation, changes in skin condition, mouth sores, shortness of breath, difficulty swallowing, and hair loss[5]. Childhood cancer is among the complex diseases that require continuous treatment and care over time[6]. Furthermore, when children encounter various symptoms linked to their illness or its therapy; their lives are significantly impacted, presenting them with formidable obstacles [7]. With the rise in cancer cases in recent years, there has been a notable increase in the number of individuals taking on the role of caregivers for cancer patients. Many of these caregivers are comprised of different family members of the patients [8].

Late-stage cancer tends to have a slower growth and spreading rate, consequently leading to a heightened impact on the well-being of family caregivers [9]. While studies highlight the significant bond between patients and their families as an involved caregiving, there are difficulties in effectively implementing their caring abilities [10].

In Iraq, family caregivers face challenges that may affect their caring ability for children diagnosed with cancer. Health

researchers must focus on improving cancer related issues and overcoming influencing factors facing parents, which contributes to providing high-quality health care to the ill children and their families.

Methods

Study Design and Setting

A descriptive design was conducted at the Hematology and Oncology Center at Welfare Teaching Hospital in the medical city directorate from January 2nd, 2024, to March 27th, 2024.

Study Sample and Sampling

A non-probability (purposive) sampling involved 200 family caregivers of children diagnosed with cancer by their physicians.

Data Collection and Study Instrument

Data were collected from 200 family caregivers selected based on inclusion criteria: willingness of family caregivers to participate in the study, ability to speak and understand Arabic language, and with no history of psychological disorders. Family caregivers' providers were also included in the study if they had experience working with cancer children. Data were collected via a self-report method between January 2nd and March 27th, 2024.

The questionnaire used in the study comprised two parts: (i) socio-demographic characteristics of family caregivers and their children with cancer, including age, sex, kinship to the child, child sex, duration of child family care, residency, family caregiver level of education, marital status, occupation, and monthly income. (ii) The level of caregivers caring measured by Caring Ability of Family Caregivers Patient Cancer Scale, developed by Nemati et al [11]. This scale encompassing sub dimensions such as effective role play (12 items), fatigue and surrender (8 items), trust (3 items), uncertainty (4 items), and caregiving ignorance (4 items). Responses were recorded on a Likert scale ranging from 1 to 5, where 1 represented "strongly disagree" and 5 indicated, "Strongly agree."

Validity and Reliability of the Instrument

The content's validity was assessed by a panel comprising of 11 experts from the College of Nursing, University of Baghdad, tow experts from the Oncology and Hematology Center at Welfare Teaching Hospital, and two experts from the Cancer Oncology Center at Baqubah Teaching Hospital, Diyala Health Directorate. Upon obtaining permission from Scale authors, the tool was translated into Arabic. Then, bilingual professors reviewed and adjusted it to suit the study's variables and community. A pilot study involving 20 participants was conducted to assess the tool's reliability through a test-retest method. Cronbach alpha correlation coefficient is computed. The result showed acceptable reliability, depending on the value of the coefficient test, which was 0.75. The original Cronbach's alpha for the questionnaire from the previous study is 0.93[11]. The pilot study sample were excluded from the original study.

Ethical Consideration

Scientific Research Ethical Committee at the University of Baghdad, College of Nursing has approved the study to be conducted. All family caregivers who have participated in the study have signed consent form that preserves participant’s rights and privacy.

Data Analysis

Data were analysis employed statistical methods, including descriptive (Standard Deviation, Mean, Frequency, Percentage) and inferential (Point-Biserial Correlation, Spearman's Correlation, Unstandardized Coefficient, Standard Error of Coefficient, Beta Coefficient, t-test) analyses, using SPSS version 24.

Results

Table1. Socio-demographic Characteristics of family caregivers (no. 200)

Variable		**Results**	
Age	Maximum and Minimum	18	68
	Mean ± SD	32.9	7.7
Variable		**F**	**%**
Sex of care giver	Male	73	36.5
	Female	127	63.5
Kinship to child	Mother	114	57
	Father	71	35.5
	Brother/sister	6	3
	Other	9	4.5
Child Sex	Girl	77	38.5
	Boy	123	61.5
Duration of patient care	1 – 12 months	84	42
	13 – 24 months	57	28.5
	25 – 36 months	34	17
	37 months and over	25	12.5
Residency	Urban	151	75.5
	Rural	49	24.5
Education level	Read and write	20	10
	Primary school graduate	24	12
	Secondary school graduate	59	29.5
	Bachelor's degree	89	44.5
	Higher studies degree	8	4
Marital status	Single	5	2.5
	Married	180	90
	Separate	10	5
	Widowed	5	2.5
Job	Employee	56	28
	Free job	35	17.5
	Housewife	72	36
	Another job/s	37	18.5
Monthly income	≤ 300.000 IQD	11	5.5
	301.000 – 600.000 IQD	22	11
	601.000 – 900.000 IQD	54	27
	901.000 – 1.200.000 IQD	60	30
	1.201.000 – 1.500.000 IQD	39	19.5
	≥ 1.501.000 IQD	14	7

F= Frequency, **%**= Percentage, **IQD**= Iraqi Dinar, ≤ = Less Than, ≥ = More Than, **SD** = Standard Deviation.

Table (1) shows that the study participants ages ranged from 18 to 68, with an average mean of 32 years. Dominant of the family caregivers (63.5%) were female, about (57%) were mothers of the children they were caring for. About 61.5% of the children with cancer were boys. The most common duration of care was 1-12 months (42%). The majority of the participants (75.5%) lived in urban areas, and 44.5% had a bachelor's degree. Additionally,

90% of the participants were married, with 36% being housewives. About 30% of the family caregivers had a monthly income between 901,000 and 1,200,000 IQD.

Table 2. Factors influencing of caring ability of family caregivers for their children with cancer

Variable	*B*	*SE B*	B	t-test	P value
Age	.002	.002	.055	.73	.46
Sex of caregiver	.042	.041	.08	1.019	.309
Kinship to child	.007	.028	.02	.24	.037
Child sex	.005	.035	.01	.144	.38
Duration of patient care	.027	.016	.116	1.68	.09
Residency	.004	.041	.007	.092	.92
Education level	.07	.019	.29	3.61	.000
Marital status	.014	.045	.023	.298	.76
Job	.004	.017	.02	.25	.79
Monthly income	.044	.015	.222	2.99	.003

B=Unstandardized Coefficient**, SEB=** Standard Error of the Coefficient**, B=** Beta**, S. =** Significant at P ≤ .05**.**

Table (2) indicates that the significant factors exploring the caring abilities of family caregivers were kinship to the children with cancer (p value= .037), caregivers' education level (p value= .000), and monthly income (p value= .003).

Table 3. Correlations between socio-demographic characteristics and family caregivers' abilities to care

Demographic characteristic	Correlations	Caring abilities domains					
		Effective role paly	Fatigue and surrender	Trust	Uncertainty	Caregiving ignorance	Total score of caring abilities
Sex of care giver	Point biserial (r)	.162	-.083	.105	.012	-.171	-.053
	Significant	.022	.244	.139	.86	.015	.45
	N	200	200	200	200	200	200
Kinship to child	Spearman's r	-.099	.003	.055	-.007	.098	.054
	Significant	.164	.96	.43	.92	.167	.449
	N	200	200	200	200	200	200
Child sex	Point biserial (r)	-.013	.027	-.097	-.022	.028	.000
	Significant	.85	.706	.174	.75	.68	.998
	N	200	200	200	200	200	200
Education level	Spearman's r	.024	.036	-.101	.063	.022	-.195
	Significant	.73	.611	.157	.37	.75	.006
	N	200	200	200	200	200	200

(r)= Point_ biserial correlation**, N=** Total number of sample.

Table (3) shows a significant correlation between the sex of caregivers and their effective role play (p= .022), while there is a negative correlation between the sex of caregivers and caregiving ignorance (p = .015). Additionally, another negative correlation is observed between the education level of caregivers and the total score of caregiving abilities (p = .006).

Discussion

The study aimed to investigate factors influencing the caring ability for children with cancer. The results showed that kinship with the child, educational level, and family income play significant roles. There was a strong correlation between the caregiver's sex and their effective role in caring for children, and an inverse correlation between the caregiver's sex and the ignorance of health care methods.

The study found that the demographic characteristics of family caregivers varied significantly. Over half of the participants were female, and this aligning with previous research found that the proportion of female caregivers exceeds that of male caregivers [(12)]. This could be explained by the fact that mothers, with their greater experience in meeting children's consistent and diverse needs, appear more skilled in providing daily care.

For children with cancer, the study findings revealed that the majority of cancer cases occur in boys rather than girls. This aligns with a prior study from Iraq, where over half of the sample were boys [(13)]. In this study, it is evident that the majority of family caregivers were married, aligning with findings from a previous study indicated that about three-quarters of the sample were married [(12)]. Furthermore, the statistical analysis indicates that over a quarter of the sample consists of housewives, consistent with another study that demonstrated the majority of mothers being housewives [(14)].

The caregiving ability of the family caregivers was positively associated with their relationship to the child with cancer, educational level, and caregivers' monthly income.

The significance of kinship of family caregivers to their children with cancer was found to be related. Kinship to children is essential in building the psychological and social support necessary for the child to face the challenges resulting from cancer. The family plays a vital role in motivating the child to adhere to treatment [(15)]. Mothers represent the majority percentage in this study, making them a crucial source of strength and security for their children during the treatment period [(16)]. This finding contrast with a study in the United Kingdom, where it is estimated that about half of kinship caregivers were grandparents [(17)].

The results of the study indicated a positive correlation between the academic educational level of family caregivers and their ability to provide care to children with cancer. This can be explained by education playing an effective role in understanding and facilitating communication with the medical team, making critical decisions regarding treatment, providing comprehensive care, and creating a positive environment for children [(18)]. A higher educational level enhances caregivers' ability to understand and apply appropriate health care to children with cancer. Education provides stress management skills, which help them deal with challenges while providing care, thus giving more effective and comprehensive care to children. [(19)].

With regard to family income, the results showed a clear indication of the effect of monthly income on the ability of family caregivers to care for their children with cancer. The monthly income can significantly affect the care ability that the child receives. A recent study indicate that low-income families may find it difficult to paid for the necessary care and treatment for their children with cancer, which can have a negative impact on treatment outcomes [(20)]. Conversely, high-income families can provide better quality medical care without worrying about costs. A supporting study reported that caregivers of cancer patients from low-income families are more likely to increase debt and loss their jobs compared to others [(21)].

Furthermore, the results of this study indicate several significant correlations between certain demographic characteristics of caregivers and their caregiving abilities in different domains.

In the current study, the result reveals that there is a significant correlation between the sex of caregivers and their effective role-playing. This suggests that female caregivers may be more adept at taking on various roles and scenarios when providing care,

potentially leading to more successful outcomes in their caregiving responsibilities. This is consistent with a study found that the highest average score was in "effective role playing" (44.62±5.28), which was associated with reduced fatigue and resignation among mothers. High levels of confidence and effective role playing contributed to this positive outcome [22].

Contrary to the presented content, there is a negative correlation between the sex of family caregivers and the level of caregiving ignorance, suggesting that males may exhibit higher levels of ignorance in caring for children with cancer, impacting their ability to perform their tasks effectively. Research indicates that mothers are often perceived as better caregivers due to their superior skill in various aspects of care, while fathers appear more competent at providing tangible and money support [23]. This disparity in abilities is due to mothers' specialization in care and responsibilities for their children, which may hinder fathers' understanding of certain aspects of care [24].

The results of this study showed a negative correlation between the education level of caregivers and the total score of caregiving abilities. This difference can be attributed to several factors, including the fact that providing care requires knowledge, skill, and experience. Caregivers with good knowledge can enhance their family's efficiency in dealing with the patient [25].

However, this study match with previous studies found that the only factor not associated with family readiness, which was the level of education [26, 27].

The goal of this study was to understand the factors that influence caregivers' ability to care for children with cancer. The study showed that kinship, educational level, and family income have a significant impact on caregivers' ability to provide effective care. The results found a positive effect of education and income on the quality of care provided. The findings highlight the importance of ongoing social and psychological support for caregivers, especially mothers, in improving the treatment experience of children with cancer.

Conclusion

The study concluded that the abilities of family caregivers for children with cancer affected by several factor. These including kinship with the child, as those closely related to the child have higher abilities in providing care. In addition, educational level and monthly income greatly affect, highlights the importance in Providing financial support and resources to caregivers. Especially to those who have low levels of education and limited financial income. Research shows that mothers constitute the majority in providing care for their children due to their physical and emotional closeness to the children. This closeness contributes to improving the abilities of caregivers and thus the well-being of children with cancer.

Recommendation

This study recommends developing tailored support programs for family caregivers, taking into account their educational backgrounds and financial situations. These programs can include educational workshops, online resources, financial assistance programs, and access to counseling services. Family caregivers should also be offered education and training opportunities to enhance their caregiving skills and increase their knowledge about cancer care. In addition, community outreach efforts should be increased to raise awareness about the challenges faced by family caregivers of children with cancer.

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Conflict of interest

None to declare.

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Data availability

The data supporting the findings of this study are not publicly available due to ethical and privacy considerations but may be made available from the corresponding author upon reasonable request and with appropriate approval.

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