Caregivers Awareness Regarding Health Care offered to their children with Ewing Sarcoma

Lamyaa Momtaz Mohamed, Prof. Dr./ Nahla Ahmed Abdalaziz
Assist. Prof. Dr./ Mona Abo Bakr Abd Ellatef,
Family and Community Health Nursing Department, Faculty of Nursing,
Ain Shams University

Abstract

Background: Ewing sarcoma is a very aggressive malignancy tumor that requires complex multidisciplinary management. **The aim of the study:** Was to assess caregivers' awareness regarding health care offered to their children with Ewing sarcoma. **Research design:** A descriptive analytical design was utilized. **Setting:** The study was conducted at outpatient clinics for bone tumors in Elbuhaira cancer center, Egypt. **Sample:** convenience sample composed of (335) caregivers caring for their children with Ewing sarcoma. **Tools:** Three tools were used. **First tool:** Structured interviewing questionnaire for caregiver was used. **Second tool:** Attitude of caregiver for children with Ewing sarcoma. **Third tool:** Observational checklist for health status of child with Ewing sarcoma. **Results:** 66.2% of the studied caregivers had un satisfactory total level of knowledge, 57.7% of them had un satisfactory total level of reported practice, and 51.3% of them had a negative attitude. 80.3% of children with Ewing sarcoma had a high health needs. **Conclusion:** There were a highly statistical significant relation between caregivers' total knowledge and their educational level, monthly income, age, and relation with child. There was a highly statistical significant relation between caregivers' total knowledge and their total reported practice, and between caregivers' total reported practice and their total children health needs. **Recommendations:** Increasing awareness of the Caregiver about Ewing sarcoma through periodically educational programmers . Further studies including larger samples of children with Ewing sarcoma and their caregivers from different geographical areas to generalize the results in Egypt.

Keywords: Caregiver, awareness, health care, Ewing sarcoma.

Introduction

Ewing sarcoma (ES) is rare, an aggressive, and metabolically active bone tumor occurring predominantly in the ribs, pelvis, femur, and tibia or soft-tissue tumor occurring predominantly in the cervical muscles, thoracic wall, pleural cavities, and gluteal muscle **(Truong et al., 2022).** The majority of ES arise in bone, and up to 30% in soft tissue **(Heller et al., 2023).** ES mainly affects children, adolescents and young adults but it can occur at any age, it is a genetically well-characterized disease with rapid tumor growth **(Ceranski et al., 2023).**

About 200-250 children and teens are diagnosed with ES in the United States each year **(Irfan et al., 2023).** The peak incidence occurs in the second decade of life (mainly age of 15) accounting 10 % to 15% of orthopedic tumors and rare in people over 30 years, is higher in males than in females with a ratio of 3:2 **(Hu and Cai, 2022),** and higher in populations of European versus African or Asian ancestry **(Kaneva et al., 2022)** despite of Asia has the highest Ewing's sarcoma prevalence **(Shashaa et al., 2022).** ES is extremely aggressive and can rapidly metastasize to the lung and other tissues although it accounts for only 1% of human malignant tumors. Symptoms of ES may be mild at first and slowly progress, or may suddenly appear. Clinical symptoms include localized pain, swelling, and may a palpable mass, fever, fatigue, weight loss, and/or anemia **(Rehman et al., 2022).** Further tests to confirm Ewing sarcoma diagnosis include CT scan, MRI Scan, biopsy of the bone, bone marrow biopsy, and blood tests **(Seth et al., 2022).**

In general, ES is difficult to treat as children with Ewing sarcoma have frequent relapses and require complex treatment regimens. Standard care for ES consists of a multimodal treatment regimen by a multidisciplinary team including surgical resection and/or local radiotherapy, also intensive multi-agent chemotherapy. Effective

delivery systems and new treatment modalities such as develop new drugs, active molecules, and combinatorial approaches is obviously needed to increase therapeutic efficacy and to deliver drugs to avoid side effects associated with non-specific chemotherapy **(Tsibulnikov et al., 2023).**

Community health nurse can take actions to raise caregivers' awareness such interventions would possibly contribute to improve the quality of life of patients, enable the optimal treatment of the patient through participating in therapeutic regimen, educating of patients and their caregiver how to deal with side effects, stress, and reduce the costs imposed on the health system and society in general. As well changing life style, maintaining appositive self-image and performing self-care to maximum level **(Antony and Thelly, 2022)** and **(Hashemlu et al., 2022).**

Significance of the study

Globally, each year, approximately 400.000 children develop cancer. In 2020, there were an estimated 18.1 million cancer cases .Of these, 9.3 million cases were in men and 8.8 million in women. Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths **(WHO, 2023).** Worldwide there will be 28 million new cases of cancer each year by 2040 **(Cancer research UK, 2023).**

The Egyptian population is one of the largest in the Middle East and North Africa region. The population in Egypt represents 1.29% of the global population. Total number of cancer cases in Egypt was 134.632 and 89,042 cancer-related deaths in 2020 **(Ahmed and Emad, 2022).**

Cancer is a dramatic event that destroys the sense of normal life activities and affects all dimension of life involves physical, psychological, emotional, and social factors. Cancer can generate feelings of fear, disorientation, and impotence. The different degrees of children with Ewing sarcoma and their caregivers' awareness of clinical situation can influence their psychological functioning including anxiety and depression level **(Lai et al., 2023).**

Aim of the study

The aim of the study is to assess caregiver awareness regarding children with Ewing sarcoma through:

1.Assessing care givers knowledge regarding Ewing sarcoma.

2.Assessing care giver reported practices toward children with Ewing sarcoma.

3.Assessing care giver attitude toward children Ewing sarcoma.

4.Assessing child with Ewing sarcoma health needs.

Research question:-

1.Is there a relation between caregiver socio-demographic characteristics and their knowledge regarding their children with Ewing sarcomas?

2.Is there a relation between caregiver knowledge and their practices toward their children with Ewing sarcoma?

3.Is there a relation between caregiver practices and their children's health status?

Subject and Methods

Subject and methods of this study were portrayed under four main designs as follows:

I. Technical design

II. Operational design

III.Administrative design

IV.Statistical design

I. Technical design

Technical design for this study included research design, research setting, and study subjects and data collection tools**,** validity, reliability of the tools.

Research Design:

A descriptive analytical design was utilized in this study.

Research Setting:

The study was conducted at in outpatient clinics for bone tumors in Elbuhaira Cancer

Center, Egypt. Elbuhaira Cancer Center serves all citizens for all ages that live in Elbuhaira governorate and it considered the biggest center where patients with cancer were treated, medical supervision available if needed referred to governmental centers.

Tools for Data Collection:

In order to fulfill the aim of the study the data was collected using the following three tools:

First Tool: Structured Interview Questionnaire Sheet:

The questionnaire was developed by researcher based on scientific review of literature and was designed on Arabic format in suitable language to suit participant's level of understanding to assess the following parts:

Part I: Interview Questionnaire Sheet:

A-Socio-demographic characteristics of caregiver:

It was consisted of 8 items to elicit the data of studied caregiver such as age, sex, their relation with child, marital Status, educational level, occupation, monthly income and number rooms in the home.

B- Demographic characteristics of children with Ewing sarcoma:

It was consisted of 4 items which includes child's age, gender, ranking of the child, and educational level.

C- Medical history of the child with Ewing sarcoma:

It was consisted of 6 items; Onset of disease diagnosis, Type of Ewing sarcoma, Site of Ewing sarcoma, Tumor Size, has previous surgery, and the type of current therapy.

Part II: Caregiver knowledge regarding health care offered to their children with Ewing sarcoma

It contained 12 questions used to assess knowledge of the caregiver about Ewing sarcoma that includes; definition, risk factors, symptoms, complications, drugs, drug precautions and feeding **(Norberg et al., 2014).**

Scoring system:

Each correct answer was scored as one score, and the wrong answer was scored as zero. These scores were summed up and converted into percentage. The total scores of the questions were 12 marks which equal 100% and accordingly the caregivers' knowledge was classified into 2 categories:

- Satisfactory knowledge if total score ≥60%. (≥ 8 to 12)

- Unsatisfactory knowledge if total score < 60% (0 to 7)

Part III: Caregivers' reported practice regarding Ewing Sarcoma

It used to assess Caregivers' practice related to caring of their children with Ewing sarcoma **(Gargallo, et al., 2020).** It include 50 items divided into 7 subscales; personal hygiene (10 items), nutrition (8 items), elimination (6 items), transferring (7), drug administration (7), pain management (6), and sleep (6).

Scoring system:

Each item was scored as one score if done, and scored as zero if not done. These scores were summed up and converted into percentage. The total score of Caregivers' practice sheet were 50 degree which equal 100%, accordingly the total Caregivers' practice was classified into 2 categories:

- Satisfactory practice if total score ≥60%. (≥ 30 to 50)

- Unsatisfactory practice if total score < 60% (0 to 29)

Second Tool: Attitude of caregiver for children with Ewing sarcoma:

The scale was adopted from Zarit Interview to assess the attitude of caregiver toward their children with Ewing sarcoma. It was consisted of a total of 22 questions divided into three domains: physical aspects of the child (7 items), psychological aspects of the child (6 items), and social aspects of the child (9) items **(Wilson et al., 2016).**

Scoring system for Attitude Interview scale:

Each sentence was answered by "always" was given two score, "sometimes" was given one score and "never" was given zero score. These scores were summed up; accordingly the total Caregivers' Attitude was classified into 2 categories:

-**Positive attitude** if total score ≥60%. (≥ 28 to 44)

- **Negative attitude** if total score < 60% (0 to 27)

Third Tool: Observational checklist for child with Ewing sarcoma:

A- Assess children with Ewing sarcoma health status

This tool used to assess children with Ewing sarcoma health status **(Wong, 2013).** It was consisted of a total of 13 items divided into two domains: Physical Health assessment (6 items) and Physical Health Problems (items7).

Scoring system for Observational checklist Scale:

Children' physical health assessment was consisted of 6 sentences, each sentence was answered by "normal" was given one score and "abnormal" was given zero score and these scores were summed up. Children' physical health problems was consisted of 7 sentences**,** each sentence was answered by "yes" was given one score and "no" was given zero score and these scores were summed up.

B:-Assessing children health needs with Ewing sarcoma:

This tool used to assess health needs for children with Ewing sarcoma .it was consist of total 38 items divided into 5 subscale : Physiological needs (11items), Psychological needs (14 items) ,Mental and cognitive needs (5items), Social needs(4 items), Medical needs (4items).

Scoring system: Each sentence was answered by always was given two score, sometimes was given one score and never was given zero.

Total scores were divided and converted in to percentage as following:

- Low health needs if total score was 45% ≥ (0-34 score).
- Moderate health needs if total score was (45 %< score ≤65%) (35- 49 score)
- High health needs if total score was (65 %< score) (50 score and more).

II. Operational design

The operational design for this study included preparatory phase, pilot study and fieldwork.

Preparatory phase:

This phase was the first of the thesis, included reviewing of past, current, local, and international, relevant literature and different studies related to the topic of research, using textbooks, articles, magazines, internet search was done to get a clear picture of all aspects related to research topic. This helped the investigator to be acquainted with magnitude and seriousness of the problem, and guided the investigator to prepare the required data collection tools.

Pilot Study:

A pilot study conducted to test the applicability of the tools, the feasibility of the study and estimate the time needed for collecting the data. It was conducted on 10% of the total sample (36 caregivers) according to the selection criteria. All caregivers participated in the pilot study excluded from the study sample.

Fieldwork /procedure of data collection:

The investigator started data collection by introducing himself to the studied caregivers and the purpose of the study was simply explained to the caregivers who agree to participate in the study**.** Each participant interviewed and assessed individually. Each caregiver was handed the questionnaire and answered it under observation of the investigator. Participant who can't read well, the researcher helped them to write their answers. The first tool (Interviewing questionnaire) filled in about 10 minutes, the second instrument

(Attitude of caregiver for children with Ewing sarcoma) filled in about 15 minutes and the third tool (Observational checklist for child with Ewing sarcoma) filled in about 5 minutes. The process of data collection took about 6 months started in the beginning of October 2021 and ended in the end of March 2022. The investigator collected questionnaires at Elbuhaira Cancer Center during the morning shift from 9 am to 12pm, two days per week (55-60 questionnaires per month).

III - Administrative design

Administrative Approval:

Official permission was obtained from the dean of the Faculty of Nursing, Ain Shams University and official permission was obtained from the director of Elbuhaira Cancer Center to obtain the approval for data collection. To conduct the proposed study, a full explanation about the aim of study was explained. The aim and the nature of the study were explained to the administrative personnel.

Ethical Considerations:

The ethical research considerations include the following:

- The research approval for protocol was obtained from the faculty ethical committee before starting the study.
- The investigator clarified the objectives and aim of the study to parents included in the study before starting.
- The investigator assured maintaining anonymity and confidentiality of data of the patients included in the study.
- Subjects were informed that they were allowed to choose to participate in the study or not and they had the right to withdraw from the study at any time
- Ethics, values, culture and beliefs were respected.
- An approval was obtained from the director of Elbuhaira Cancer Center.

IV -Statistical design

Upon completion of data collection, the collected data were organized, tabulated; The statistical analysis of data was done by using the computer software of Microsoft Excel Program and Statistical Package for Social Science (SPSS) version 22. Data were presented using descriptive statistics in the form of frequencies and percentage for categorical data, the arithmetic mean (X) and standard deviation (SD) for quantitative data. Qualitative variables were compared using chi square test (X) 2, P-value to test association between two variables and Pearson correlation test (R- test) to the correlation between the study variables.

Degrees of significance of results were considered as follows:

- P-value > 0.05 Not significant (NS)
- P-value ≤ 0.05 Significant (S)
- P-value ≤ 0.01 Highly Significant (HS).

Results

Part I: Socio-demographic characteristics of the studied caregivers.

Table (1): displays that, (38.0%) of the studied caregivers their age ranged between 35-<40 years, the Mean SD of age was 38.41 ± 6.07 years. As regard to gender and marital status, (85.1% and 93.2%) of the studied caregivers were female and married, respectively. Also, (56.6%) of the studied caregivers were mothers. Moreover, (63.4%) of them were house wife. Also, (53.5%) of them had secondary education. Furthermore, (71.8%) of the studied caregivers do not had enough monthly income. Moreover, (64.2%) of them had 2 rooms.

Figure (1): shows that, (66.2%) of the studied caregivers had unsatisfactory level of total knowledge regarding Ewing sarcoma**.** While, (33.8%) of them had satisfactory level of total knowledge.

Figure (2) shows that, (57.7%) of the studied caregivers had unsatisfactory level of total reported practice regarding Ewing

Sarcoma. While, (42.3%) of them had satisfactory level of total reported practice**.**

Figure (3) displays that, (51.3%) of the studied caregivers had negative attitude for children with Ewing sarcoma. While, (48.7%) of them had positive attitude for children with Ewing sarcoma**.**

Part II: Relationship between the studied variable.

Table (2) Answer research question No (1), Is there a relation between caregiver socio-demographic characteristics and their knowledge regarding their children with Ewing sarcomas?

Table (2): Displays that, there were highly statistically significant relation between total caregivers' knowledge and their education level and monthly income at ($P < 0.001$). Also, there were statistically significant relation with their age, caregiver relation with child at ($P < 0.05$). While, there were no statistically significant relation with their gender, marital status, occupation and number of rooms at ($P > 0.05$).

Table (3) Answer research question No (2), Is there a relation between caregiver knowledge and their practices toward their children with Ewing sarcoma?

Table (3): shows that, there were highly statistically significant relation between total knowledge of the studied caregivers and their total reported practice and attitude for children with Ewing sarcoma at ($P < 0.001$).

Table (4) Answer research question No (3), Is there a relation between caregiver practices and their children's health needs?

Table (4): shows that, there were highly statistically significant relation between total reported practice of the studied caregivers and their total children's health needs at ($P < 0.001$).

Table (1): Frequency distribution of the studied caregivers according to their socio-demographic characteristics **(n=355).**

Items	No.	%
Age		
25-< 30 years	65	18.3
30-<35 years	87	24.5
35-<40 years	**135**	**38.0**
≥ 40 years	68	19.2
Mean ± SD **38.41 ± 6.07**		
Gender		
Female	**302**	**85.1**
Male	53	14.9
Caregiver relation with child		
Father and mother	113	31.8
Father only	35	9.9
Mother only	**201**	**56.6**
One of the maternal grandparents	2	0.6
One of the paternal grandparents	4	1.1
Marital Status		
Married	**331**	**93.2**
Divorced	12	3.4
Widow	12	3.4
Occupation		
Free business	33	9.3
Employee	55	15.5
House wife	**225**	**63.4**
Not work	42	11.8
Educational level		
Not read and not write	18	5.1
Read and write	33	9.3
Basic education	65	18.3
Secondary education	**190**	**53.5**
University education	49	13.8
Monthly Income		
Enough	100	28.2
Not Enough	**255**	**71.8**
Number of rooms		
<2 rooms	20	5.6
2 rooms	**228**	**64.2**
3 to 5 rooms	107	30.2

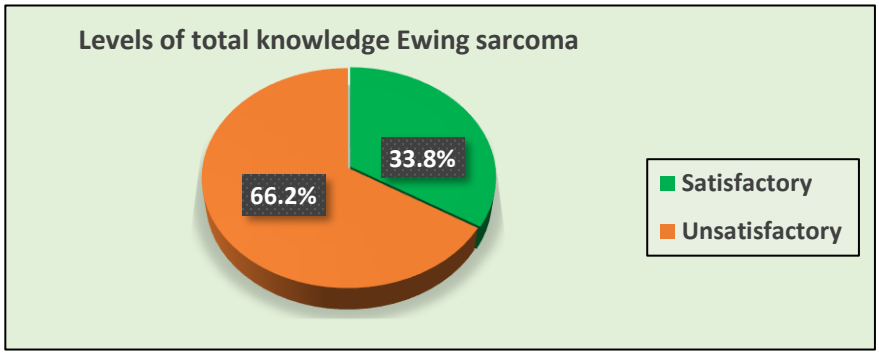

Figure (1): Percentage distribution of the studied caregivers according to their total knowledge regarding Ewing sarcoma **(n=355).**

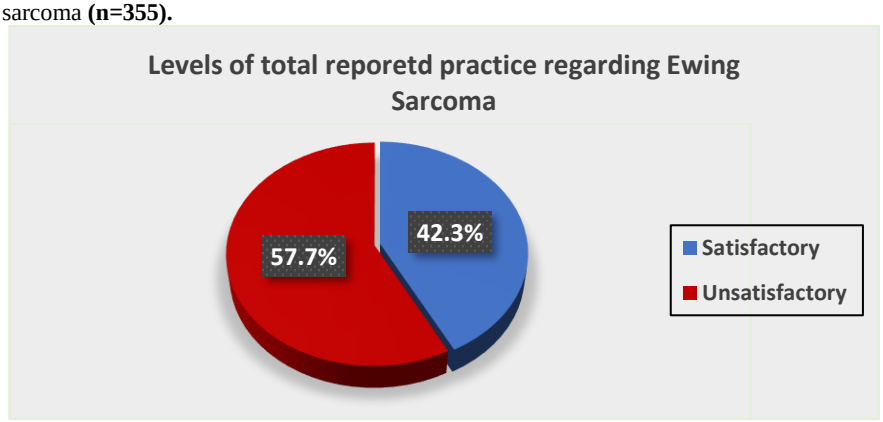

Figure (2): Percentage distribution of the studied caregivers according to their total reported practice regarding Ewing Sarcoma **(n = 355).**

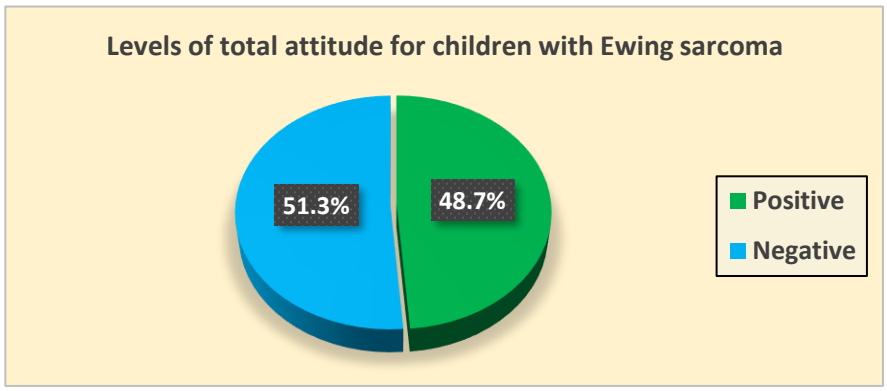

Figure (3): Percentage distribution of the studied caregivers according to their total attitude for children with Ewing sarcoma **(n = 355).**

Table (2): Relationship between socio-demographic characteristics of the studied caregivers and their total knowledge regarding Ewing Sarcoma **(n=355).**

Socio-demographic characteristics		Levels of total knowledge				X^2	P-Value
		Satisfactory (n=120)		Unsatisfactory (n=235)			
		No.	%	No.	%		
Age (years)	25-< 30	5	4.2	60	25.5	13.54	0.029*
	30-<35	12	10.0	75	31.9		
	35-<40	68	56.6	67	28.5		
	≥ 40	35	29.2	33	14.1		
Gender	Female	82	68.3	220	93.6	5.364	0.137
	Male	38	31.7	15	6.4		
Caregiver relation with child	Father and mother	85	70.8	28	11.9	12.70	0.031*
	Father only	30	25.0	5	2.1		
	Mother only	5	4.2	196	83.4		
	One of the maternal grandparents	0	0.0	2	0.9		
	One of the paternal grandparents	0	0.0	4	1.7		
Marital Status	Married	111	92.5	220	93.6	3.922	0.141
	Divorced	5	4.2	7	3.0		
	Widow	4	3.3	8	3.4		
Occupation	Free business	30	25.0	3	1.3	2.933	0.204
	Employee	35	29.2	20	8.5		
	House wife	53	44.2	172	73.2		
	Not work	2	1.6	40	17.0		
Education level	Not read and not write	0	0.0	18	76.6	22.74	0.000**
	Read and write	0	0.0	33	14.1		
	Basic education	5	4.2	60	25.5		
	Secondary education	70	58.3	120	51.1		
	University education	45	37.5	4	1.7		
Monthly Income	Enough	97	80.8	3	1.3	21.01	0.000**
	Not Enough	23	19.2	232	98.7		
Number of rooms	<2 rooms	10	8.3	10	4.3	1.747	0.226
	2 rooms	43	35.8	185	78.7		
	3 to 5 rooms	67	55.9	40	17.0		

No significant at p > 0.05. * Statistically significant at p ‹ 0.05. **Highly statistically significant at p ‹ 0.001.

Table (3): Relationship between total knowledge of the studied caregivers and their total reported practice and attitude for children with Ewing sarcoma **(n=355).**

Variables		Levels of total knowledge				X^2	P-Value
		Satisfactory (n=120)		Unsatisfactory (n=235)			
		No.	%	No.	%		
Levels of reported practice	Satisfactory	118	98.3	32	13.6	61.98	0.000**
	Unsatisfactory	2	1.7	203	86.4		
Levels of attitude	Positive	118	98.3	55	23.4	54.51	0.000**
	Negative	2	1.7	180	76.6		

****Highly statistically significant at p ‹ 0.001.**

Table (4): Relationship between total reported practice of the studied caregivers and their total children's health needs **(n=355).**

Levels of total children's health needs	Levels of total reported practice				X^2	P-Value
	Satisfactory (n=150)		Unsatisfactory (n=205)			
	No.	%	No.	%		
High	95	63.3	190	92.7	21.39	0.000**
Moderate	40	26.7	15	7.3		
Low	15	10.0	0	0.0		

****Highly statistically significant at p ‹ 0.001.**

Discussion

Ewing sarcoma is the second most common malignant pediatric bone tumor with a peak incidence in adolescence. When a child has Ewing sarcoma, caregivers may have an additional range of responsibilities. These may include giving medications or managing symptoms and side effects. A caregiver plays a very important role in supporting a child or young adult diagnosed with Ewing sarcoma, providing physical, emotional, and practical care on a daily or as-needed basis. Many caregivers become focused on providing this support, especially if the treatment period lasts for many months or longer **(Weber et al., 2022).**

Part I: Socio-demographic characteristics of the studied caregivers.

Regarding socio-demographic characteristics of the studied caregivers, the present study revealed that more than one third of the studied caregivers their age ranged between 35-<40 years, the Mean SD of age was 38.41 ± 6.07 years. This result was similar to **Ahmadi et al., (2021)** who conducted study in Iran entitled "Predictors of caregiver burden among parents of children with cancer" (n=125), and found that the mean age of the studied parents was 40.16 ± 5.23 years old.

Concerning the studied caregivers' gender and marital status, the current study illustrated that most of them were female and married. This result was in the same line with **Chaghazardi et al., (2022)** in Sudan, whose study entitled "Care burden and associated factors in caregivers of children with cancer", (n= 270) who reported that most of the studied care givers were female (70%) and married (90.4%).

As regard the studied caregivers' relation with the child and their caregivers occupation, more than half of them were mothers and nearly two thirds of them were house wives. Similarly, a study in Egypt performed by **Ahmed et al., (2022)**, about "Assessment of Parental Caring for Children with Cancer on Their Quality of Life", (n= 150) and found that most of the studied caregivers were mothers and not working. From the research investigator point of view, this can be attributed to the fact that the essential role of mothers is taking care of their children and family.

According to the studied caregivers' level of education educational, the current study indicated that more than half of them had secondary education. This result was inconsistent with **Al-Dhawyani et al., (2022)** who conducted a study entitled "Factors contributing to the unmet needs of primary caregivers in Omani children diagnosed with leukemia" (n= 119), and reported that less than 30%of the studied caregivers had secondary education. This discrepancy may be related to sociocultural and socioeconomic differences between both study samples.

Related to monthly income of the studied caregivers, the current study declared that more than two thirds of the studied caregivers do not had enough monthly income. Moreover, nearly two thirds of them had 2 rooms. Likewise, a study in Iran conducted by **Khademi et al., (2019)** about "Caring power of mothers who have a child with cancer and its predictors", (n= 196) and reported that the more than two thirds of the studied mothers hadn't enough monthly income and had two rooms in their house.

On contrary, a study conducted by **Vennila, (2020)** in India, whose study entitled

"A study to assess the Impact of nurse–led mothers empowerment program on homecare management of child with Leukemia at Pediatric Tertiary Care Hospital, Chennai", (n= 60) and found that nearly two thirds of the studied mothers had adequate family income. From the research investigator point of view, assessment of family income is necessary as it relates to good mangement of disease.

Part II: Levels of total knowledge Ewing sarcoma

Concerning total knowledge of the studied caregivers regarding Ewing sarcoma, the present study reflected that about two thirds of the studied caregivers had unsatisfactory level of total knowledge regarding Ewing sarcoma**,** while about one third of them had satisfactory level of total knowledge. This result was in harmony with **Hasan et al., (2020)** who stated that there was unsatisfactory knowledge among most of mothers having children with cancer. From the research investigator point of view, this may be related to caregivers' level of education and lack of health education programs to raise the caregivers' awareness regarding Ewing sarcoma.

Part III: Levels of total reported practice regarding Ewing sarcoma.

The current study clarified that more than half of the studied caregivers had unsatisfactory level of total reported practice regarding Ewing Sarcoma, while more than two fifths of them had satisfactory level of total reported practice. This result was supported by **Alseraty & Amin, (2019)** who studied "Effects of Maternal Capacity Building Intervention on their Competence, Perceived Wellbeing and their Leukemic Children Health" in Egypt, (n= 54) and mentioned that most of the studied mothers had low level of competence regarding care before intervention.

Part IV: Levels of total attitude for children with Ewing sarcoma

The studied caregivers' total attitude for children with Ewing sarcoma, the current study represented that more than half of the studied caregivers had negative attitude for children with Ewing sarcoma, while nearly half of them had positive attitude for children with Ewing sarcoma. These findings was in the same line with a study in United kingdom conducted by **Makhlouf et al., (2020)**, who studied "Managing pain in people with cancer-a systematic review of the attitudes and knowledge of professionals, patients, caregivers and public", and reported that the majority of studies with cancer patients reported that the mean scores on caregivers' attitudes towards care were low. This may be related to the studied caregivers' level of knowledge.

Relationship between the studied variable:

Answer research question No (1), "Is there a relation between caregiver socio-demographic characteristics and their knowledge regarding their children with Ewing sarcomas?"

Regarding relationship between socio-demographic characteristics of the studied caregivers and their total knowledge regarding Ewing Sarcoma, the current study indicated that there were highly statistically significant relations with their education level and monthly income. Also, there were statistically significant relations with their age and caregiver relation with child, while there were no statistically significant relations with their gender, marital status, occupation and number of rooms. This can be interpreted as older caregivers and those who have higher levels of education and have sufficient monthly income are more likely to have satisfactory level of knowledge than others. Also, father and mother together have more knowledge than other caregivers.

This result agreed with a study in Egypt carried out by **Mohamed et al., (2019)** about "Effect of Discharge Plan for Children undergoing Chemotherapy and Their Caregivers on Improving Practice and Coping Pattern", (n= 50) and reported that there were significant relations between the studied caregivers level of knowledge and their age, educational level and monthly income. On the other hand, **Hasan et al., (2020)** who found that there were no statistically significant relationships between the total mean scores of mothers' knowledge and their personal data as age, level of education and income.

Concerning relationship between socio-demographic characteristics of the studied caregivers and their total reported practice regarding Ewing Sarcoma, the present study declared that there were highly statistically significant relations with their age, gender, education level and monthly income. Also, there were statistically significant relations with their caregiver relation with child and number of rooms. While, there were no statistically significant relation with their marital status and occupation. This can be explained as caregivers who are older, females, with high level of education and those who have sufficient monthly income are more likely to have satisfactory level of practice than others. Also, caregivers who are father and mother together and have little number of rooms are more likely to have more knowledge than other caregivers.

These results was supported by a study conducted by **Khademi et al., (2019)** who asserted that variables of age, educational level, and adequacy of family income had a significant relation with mothers level of care practices. In the opposite line, a study in Iraq carried out by **Saeed et al., (2021)** entitled "Structured teaching programme enhances the knowledge of mothers to take care of children with leukaemia", (n= 109) and found that all demographic characteristics of the mother were not associated with the mothers' level of practice.

Regarding relationship between socio-demographic characteristics of the studied caregivers and their total attitude for children with Ewing sarcoma, the present study illustrated that there were highly statistically significant relations with their age, education level and monthly income, while there were no statistically significant relations with their gender, caregiver relation with child, marital status, occupation and number of rooms. This can be interpreted as caregivers who are older, with high level of education and sufficient monthly income are more likely to have positive attitude than other caregivers. Conversely, this result disagreed with a study by **Sen, (2020)** who stated that on statistical analysis, mother's age, educational status or family income did not influence their attitude.

As regard relationship between socio-demographic characteristics of the studied children and their total health needs, the current study revealed that there was highly statistically significant relation with their age. Also, there were statistically significant relations with their ranking of the child and educational level, while there was no statistically significant relation with their gender. This can be explained as children who are older, ranked second child and who are at preparatory school are more likely to have high level of health needs. This result agreed with **Kohi et al., (2019)** who reported that child age was associated with a higher level of needs. This result was against **Elhussieny et al., (2022)** who mentioned that there were no significant relations between the studied children and their demographic characteristics.

Pertaining to relationship between medical history of the studied children and their total health needs, the present study showed that there was statistically significant relation with their onset of disease diagnosis, and tumor size. While, there were no statistically significant relations with their type of Ewing sarcoma, site of Ewing sarcoma and history of previous surgery. This can be interpreted as children who were diagnosed ≤ 24 months ago and who had 50–100 mm tumor seems to have high level of health needs. This result was similar to **Ringash et al., (2018)** who found that there was significant relation between past medical history and health needs of the studied patients.

Answer research question No (2), "Is there a relation between caregiver knowledge and their practices toward their children with Ewing sarcoma?"

As regard relationship between total knowledge of the studied caregivers and their total reported practice and attitude for children with Ewing sarcoma, the current study result declared that there were highly statistically significant relation between total knowledge of the studied caregivers and their total reported practice and attitude for children with Ewing sarcoma. This can be explained as the more the caregivers have knowledge the more they are competent and have positive attitude.

This result was congruent with **Mohamed et al., (2019)**, who asserted that

there was significant relation between knowledge and practice. Likewise, **Mohammed et al., (2018),** who reported that there were significant relation between knowledge, practice and attitude of care givers. In contrast, **Saeed et al., (2021),** they stated that there wasn't relation between mothers' knowledge and practice.

Answer research question No (3), "Is there a relation between caregiver practices and their children's health needs?"

Concerning relationship between total reported practice of the studied caregivers and their total children's health needs, the present finding reflected that there were highly statistically significant relation between total reported practice of the studied caregivers and their total children's health needs. This can be interpreted as level of children's health needs is affected by the caregivers' level of practice regarding care. This finding was in accordance to a study by **Alseraty & Amin, (2019)** stated that there was significant relation between child health needs and mother's level of practice.

Regarding relationship between total reported practice of the studied caregivers and their total attitude for children with Ewing sarcoma, the present study displayed that there was highly statistically significant relation between total reported practice of the studied caregivers and their total attitude for children with Ewing sarcoma. This can be explained as caregivers who have positive attitude seem to have satisfactory level of practice regarding the child care. This result was supported by **Yoo et al., (2018),** they found that there was a significant relation between the studied caregivers' attitude and level of practice.

As regard relationship between total reported practice of the studied caregivers and their children's health status, the current study clarified that there was statistically significant relation between total reported practice and all items of physical health assessment, and all items of physical health problems of the studied children. This can be interpreted as level of caregivers practice is affected by their child health status. This finding was consistent with **Mohamed et al., (2019)** who declared that there was significant relation between the children health conditions and their caregivers' level of practice.

Conclusion

In the light of the study results and answers of the research questions, the present study concluded that:

There were a highly statistical significant relation between caregivers' total knowledge and their educational level, monthly income (p. value <.001), while with their age, relation with child at (p. value<.05). There was a highly statistical significant relation between caregivers' total knowledge and their total reported practice (p. value <.001). There was a highly statistical significant relation between caregivers' total reported practice and their total children health needs (p. value <.001).

Recommendations

- The findings of this study highlighted the following recommendations:

1.Conducting educational programs periodically and regularly for children's and their caregivers to improve their knowledge and practices regarding Ewing sarcoma disease at outpatients' clinics or at home by nurses.

2.Availability of relevant written and visual information in Ewing sarcoma out patient's clinic to facilitate the education of children's and their caregivers about Ewing sarcoma disease such as educational booklets and brochures.

3.Conducting nutrition counselling cession regularly by nurses or by dietitians at outpatient clinics for children's and their caregivers to overcome Ewing sarcoma related nutritional problems and enhance normal growth of children.

4.Supporting of full coverage of universal health insurance system to cover Ewing sarcoma financial treatment expenses.

5.Further studies including larger sample size of children's with Ewing sarcoma and their caregivers from different geographical areas to generalize the results in Egypt.

Reference

Ahmed, H. I., El-Sayed, L. A., & El-Nagger, N. S. (2021). Effect of an Intervention Program for Caregivers of Children Suffering from Acute Lymphocytic Leukemia on their Coping Patterns.

Alseraty, W. H., & Amin, F. M. (2019). Effects of Maternal Capacity Building Intervention on their Competence, Perceived Wellbeing and their Leukemic Children Health. *International journal of Nursing Didactics*, *9*(04), 01-09.

Antony, L., & Thelly, A. S. (2022). Knowledge on prevention of pressure ulcers among caregivers of patients receiving home-based palliative care. Indian Journal of Palliative Care, 28(1), 75.

Ceranski, A. K., Carreño-Gonzalez, M. J., Ehlers, A. C., Colombo, M. V., Cidre-Aranaz, F., & Grünewald, T. G. (2023). Hypoxia and HIFs in Ewing sarcoma: new perspectives on a multi-facetted relationship. Molecular cancer, 22(1), 1-15.

Deng, L. X., Sharma, A., Gedallovich, S. M., Tandon, P., Hansen, L., & Lai, J. C. (2023). Caregiver burden in adult solid organ transplantation. Transplantation, 107(7), 1482-1491.

Elhussieny Mohammed, A., EL-Sayed Hassen, S., & A Ali, E. (2022). Needs and Problems of children Undergoing chemotherapy and their Caregivers: An assessment study. *Egyptian Journal of Health Care*, *13*(2), 670-679.

Hasan, E. S. G., Mohamed, S. A. R., Ahmed, S. M., Riad, K. F., & Ali, A. S. (2020). Knowledge and Performance of Mothers Having Children with Cancer Undergoing Chemotherapy. *Minia Scientific Nursing Journal*, *8*(1), 65-74.

Hashemlu, L., Esmaeili, R., Bahramnezhad, F., & Rohani, C. (2022). The experiences of home care team members regarding the needs of family caregivers of heart failure patients in home health care services in Iran: A qualitative study. Arya Atherosclerosis, 18(4), 1.

Hu, X., Li, D., & Cai, J. (2022). Experience of CT diagnosis and management of primary renal Ewing's sarcoma: A retrospective analysis of 6 cases and a literature review. Medicine, 101(49).

Irfan, M., Abdelsamad, O., Grezenko, H., Patel, A., & Akram, M. R. (2023). Brain Metastasis With a Solitary Lesion Secondary to Knee Joint Ewing Sarcoma: A Case Report. Cureus, 15(5).

Kohi, T. W., von Essen, L., Masika, G. M., Gottvall, M., & Dol, J. (2019). Cancer-related concerns and needs among young adults and children on cancer treatment in Tanzania: a qualitative study. *BMC cancer*, *19*, 1-9.

Lai, C., Aceto, P., Pellicano, G. R., Servidei, G., Gambardella, A., & Lombardo, L. (2022). Will I or my loved one die? Concordant awareness between terminal cancer patients and their caregivers is associated with lower patient anxiety and caregiver burden. European Journal of Cancer Care, 31(6), e13546.

Lopez Leon, A., Carreno Moreno, S., & Arias-Rojas, M. (2021). Relationship between quality of life of children with cancer and caregiving competence of main family caregivers. *Journal of Pediatric Oncology Nursing*, *38*(2), 105-115.

Mohamed, A.S., Taha, M., Khalid, W.Z. (2019). Effect of Nursing Instructions on Knowledge and Practice of Mothers Having Children with Leukemia Undergoing Chemotherapy. *The Medical Journal of Cairo University*, *87*(June), 2447-2458.

Mohammed, A. Q., Badr, S. H., & Muslem, M. S. (2018). Assessment of Caregivers' Awareness about Home Care of Neutropenia among Children with Leukemia at Oncology Wards in Baghdad City. *Indian Journal of Public Health Research & Development*, *9*(12).

Ringash, J., Bernstein, L. J., Devins, G., Dunphy, C., Giuliani, M., Martino, R., & McEwen, S. (2018, January). Head and neck cancer survivorship: learning the needs, meeting the needs. In *Seminars in radiation oncology* (Vol. 28, No. 1, pp. 64-74). WB Saunders.

Saeed, N. A. A. A., Hamzah, I. H., & Nitavid, A. (2021). Structured teaching programme enhances the knowledge of mothers to take care of children with leukaemia. *Journal of Public Health*, *29*, 55-60.

Sen, S. (2020). Parents' knowledge and attitude regarding their child's cancer and effectiveness of initial disease counseling in pediatric oncology patients.

Seth, N., Seth, I., Bulloch, G., Siu, A. H. Y., Guo, A., Chatterjee, R., ... & Donnan, L. (2022). 18F-FDG PET and PET/CT as a diagnostic method for Ewing sarcoma: A systematic review and meta-analysis. Pediatric Blood & Cancer, 69(3), e29415.

Shashaa, M. N., Alkarrash, M. S., Kitaz, M. N., Hawash, S., Otaqy, M. B., Tarabishi, J., ...

& Alloush, H. (2022). Ewing's sarcoma in scapula, epidemiology, clinical manifestation, diagnosis and treatment: A literature review. Annals of Medicine and Surgery, 77, 103617.

Truong, D. D., Lamhamedi-Cherradi, S. E., & Ludwig, J. A. (2022). Targeting the IGF/PI3K/mTOR pathway and AXL/YAP1/TAZ pathways in primary bone cancer. Journal of Bone Oncology, 33, 100419.

Tsibulnikov, S., Fayzullina, D., Karlina, I., Schroeder, B. A., Karpova, O., Timashev, P., & Ulasov, I. (2023). Ewing sarcoma treatment: a gene therapy approach. Cancer Gene Therapy, 1-6.

Weber, D. C., Beer, J., Kliebsch, U. L., Teske, C., Baust, K., Walser, M., ... & Calaminus, G. (2022). Quality-of-life evaluations in children and adolescents with Ewing sarcoma treated with pencil-beam-scanning proton therapy. *Pediatric blood & cancer*, *69*(12), e29956.

Wolyniec, K., Sharp, J., Fisher, K., Tothill, R. W., Bowtell, D., Mileshkin, L., & Schofield, P. (2022). Psychological distress, understanding of cancer and illness uncertainty in patients with Cancer of Unknown Primary. Psycho-Oncology, 31(11), 1869-1876.

Yoo, S. H., Kim, M., Yun, Y. H., Keam, B., Kim, Y. A., Kim, Y. J., ... & Jung, K. H. (2018). Attitudes toward early palliative care in cancer patients and caregivers: a Korean nationwide survey. *Cancer medicine*, *7*(5), 1784-1793.