

## Effect of Educational Guidelines on Mothers' Knowledge, Reported Practices, and Anxiety regarding their Children having Ewing Sarcoma

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### Abstract

**Background:** Ewing tumors, also called Ewing sarcomas, are a class of malignancies that originate in the surrounding soft tissues or bones and have a few characteristics as common. Though they can appear in any age group, older kids and teenagers, it mostly affects adolescents. Ewing sarcoma is a highly metastatic form of sarcoma and the second most common primary malignant bone tumor that causes severe consequences worldwide, including increased concern and anxiety among mothers over their children's health. Childhood cancers like Ewing sarcoma profoundly affect families emotionally, financially, and socially. **Aim:** To evaluate the effect of educational guidelines on mothers' knowledge, reported practices, and anxiety level regarding their children having Ewing sarcoma. **Design:** To achieve this study aim, a quasi-experimental research design was used. **Setting:** This study was applied in the Pediatric Outpatient Clinic for bone tumors at Sohag University Hospital in Egypt. **Sample:** A convenient sample of 300 mothers. **Tools:** Three tools were utilized: Tool I: Mothers' knowledge regarding Ewing Sarcoma, Tool II: Mothers' reported practices regarding Ewing Sarcoma, and Tool III: Zung's self-rating anxiety questionnaire. **Results:** The study findings revealed that mothers had a higher knowledge score and reported practices post-educational guidelines implementation than pre-educational guidelines implementation regarding Ewing Sarcoma. There was a decrease in the studied mothers' anxiety levels post-the educational guidelines implementation. There was a positive correlation between mothers' total knowledge, reported practices, and anxiety level post-educational guidelines implementation. **Conclusion:** According to the study's findings, mothers' knowledge, practices, and anxiety levels are all improved when educational guidelines about Ewing Sarcoma are implemented. **Recommendations:** To assist in psychological adjustment, it is crucial to offer mothers a well-thought-out health education program that will enhance their understanding and practice of Ewing Sarcoma and reinforce potential interventions.

**Keywords:** Anxiety, Children having Ewing Sarcoma, Educational Guidelines, Knowledge, Practices, Mothers.

### Introduction

The term "classic" Ewing sarcoma refers to Ewing sarcoma of the bone, extra-skeletal Ewing sarcoma, Askin tumors, which are malignant small cell tumors of the chest wall, and primitive neuroectodermal tumors based on soft tissues. Mesenchymal progenitor cells are the source of these sarcomas, as evidenced by their

comparable histologic and immunohistochemical features (Durer et al., 2024). The tumors belonging to the Ewing sarcoma family are distinguished by non-random chromosomal translocations that result in fusion genes that represent aberrant transcription factors. While t (21;12) (22;12) and other less common translocations generated EWS-ERG fusion includes the remaining 10% to 15% of

instances, the t (11;22) (q24; q12) translocation is linked to 85% of cancers and results in EWS-FLI-1 production (Chodyla et al., 2022). Among all bone malignancies (8394) registered, 1301(15.5%) cases were Ewing sarcoma of bone in the five PBCRs. In the childhood (0–14 years) group, Ewing sarcoma accounted for 577 (38.8%) of all bone malignancies in the population-based cancer registries (Chakraborty et al., 2018).

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. 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 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 . 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).

Types of Ewing Sarcoma included Ewing sarcoma of bone. This is the most prevalent tumor in this family is Ewing sarcoma which originates in a bone. Dr. James Ewing initially defined this kind of tumor in 1921 after determining that it differed from osteosarcoma, a more prevalent bone tumor. Its cells did not resemble osteosarcoma cells when viewed under a microscope. Additionally, it had a higher chance of responding to radiation treatment. Although they begin with the soft tissues around bones, Extra Osseous Ewing tumors (EOE) resemble Ewing sarcomas in appearance and behavior. An alternative name for them is extra skeletal Ewing sarcomas (Shashaa et al., 2022).

The Peripheral primitive neuroectodermal tumor (PPNET) is uncommon juvenile cancer shares many characteristics with Ewing sarcoma of bone and EOE, and it also begins in bone or soft tissue. Askin tumors are peripheral PNETs that originate in the chest wall (Antony &Thelly, 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 (Antony &Thelly, 2022) .

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

A crucial role is played by the mother, who is the children's primary caregiver. They have been associated with despair and anxiety. This condition can raise a child's risk of contracting it and have several negative effects, including making mothers more fearful and anxious about the health of their offspring. According to Brooks et

**al. (2020)**, mothers of children may also experience psychological pain from other sources, such as their children's safety and well-being.

Mothers are more worried about the safety and health of their children. Since they have access to the technology, they need to educate their children at home and enough food to eat, mothers are inclined to worry about their children (**Lunna et al., 2020**).

Misconceptions and a lack of knowledge may therefore fuel anxiety and psychological pain. Mothers may have different information needs, therefore evaluating their knowledge is especially important for identifying gaps and strengthening current preventive measures (**Podder et al., 2019**). For mothers to manage their anxiety and adapt to this new circumstance, they need to be given the right information, asked about their fears "both real and imagined," taught how to recognize and confront their negative thoughts, and given a sense of control over their children's social safety (**Shashaa et al., 2022**).

Concerning the management of Ewing Sarcoma, chemotherapy is considered the first step in treating. Chemotherapy is given in cycles to shrink the tumor and treat potential metastasis. The first set of drugs often includes vincristine, doxorubicin (Adriamycin), and cyclophosphamide (VAC). After the first set, ifosfamide and etoposide (IE) may be given. Pediatric patients usually receive about 14 cycles of chemotherapy over 30 to 45 weeks. Also, radiation therapy may be used to treat bone tumors or to relieve symptoms. It may be used before surgery to remove tumors that have spread to the lungs. After chemotherapy, surgery may be used to remove tumors (**Durer et al., 2024**).

Bispecific T cell engagers (BiTEs), chimeric antigen receptor T(CAR-T) cells, and monoclonal antibodies are examples of novel targeted therapeutics. These

treatments have the potential to be more comfortable for patients and more successful. In addition, nanofibers can be used to accelerate cell expansion in vitro, which could help prepare cells for HSCT (Hematopoietic stem cell therapy) (**Antony &Thelly, 2022**) .

Pediatric and Community health nurses can take actions to raise caregivers' awareness. Such interventions would possibly contribute to improving the quality of life of patients, enable the optimal treatment of the patient through participating in therapeutic regimen, educating pediatric patients and their caregivers how to deal with side effects, stress, and reduce the costs imposed on the health system and society in general. As well as changing lifestyle, maintaining a positive self-image, and performing self-care to the maximum extent are essential components of holistic recovery level (**Antony &Thelly, 2022**) .

Regarding pain management, the nurse assesses the level of pain and manages it with appropriate pharmacological and non-pharmacological approaches and ensures adequate pain relief. Develop and modify pain management strategies in conjunction with the pain management team. Psychosocial Support needs to address the emotional distress and anxiety associated with a cancer diagnosis through encourage open communication and provide information about available support services (**Antony &Thelly, 2022**) .

The preparation of Pediatric patients and family for surgery, need to be addressing their questions, concerns, risks and benefit. Discussing the prognosis and the clarifications to the Pediatric patients and families along with the surgical teams. Furthermore, monitoring the Pediatric patients closely after surgery, assessing vital signs, surgical site infections, complications, administer prescribed medications and providing wound care as needed are considered the remarkable

nursing intervention post operatively (Hashemlu et al., 2022).

As directed, promote movement and exercise within the pediatric patient's limits to avoid complications like thromboembolism, joint contractures, and muscle atrophy. They recommended collaborating with physical and occupational therapists to develop individualized rehabilitation plans. Recognize the nutritional status and provide a balanced diet to support healing and recovery. Work together with the dietitian for specific nutritional needs (Antony & Thelly, 2022).

Related to the area of Infection Prevention, the pediatric nurse must adhere to strict aseptic techniques during patient care and educate the pediatric patient and their families about the prevention of infection. In the same importance administer chemotherapy and other medications as prescribed, closely monitoring for potential side effects and complications. As well, provided education on the medication regimen and symptom management (Hashemlu et al., 2022).

### Significance of the study

Globally, each year, approximately 400,000 children and adolescents develop cancer. Of these, 105,000 children die annually. Cancer is a leading cause of death worldwide, accounting for ten million deaths (Shashaa et al., 2022). Worldwide there will be twenty-eight million new cases of cancer each year by 2040. The Egyptian population is one of the largest in the Middle East and North Africa region. Total number of cancer cases in Egypt was 134,632 and 89,042 cancer-related deaths in 2020 (Ahmed et al., 2021).

Cancer is a dramatic event that destroys the sense of normal life activities and affects all dimensions 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).

Assessing mothers' awareness and knowledge is essential in this situation since they may have an impact on the awareness of their general children. Based on the information mentioned above, the current study was created to assess general public knowledge about Ewing Sarcoma disease as part of prevention and health promotion, as well as to increase awareness, improve attitudes, and lessen concern about the current illness (Wolyniec et al., 2022). Additionally, in countries with inadequate healthcare systems, evaluating the relationship between disease knowledge and attitude might help people understand how people seek healthcare and follow preventative measures (Saeedet al., 2021). Hence, the study was done to evaluate the effect of educational guidelines on mothers' knowledge, practices, and anxiety regarding their children having Ewing sarcoma.

### Subjects and Methods

#### Research design

To achieve this study, aim a quasi-experimental research design was used a pre and post-test.

#### Aim of the study

To evaluate the effect of educational guidelines on mothers' knowledge, reported practices, and anxiety regarding their children having Ewing sarcoma through:

- Assessing mothers' knowledge level regarding their children having Ewing sarcoma pre- and post-educational guidelines.
- Assessing mothers' reported practice level regarding their children having Ewing sarcoma pre- and post-educational guidelines.

- Assessing mothers' anxiety level regarding their children having Ewing sarcoma pre- and post-educational guidelines.
- Finding out how mothers' knowledge, practices, and anxiety levels before and after educational guidelines about their children's Ewing sarcoma correlate to one other.

### Research hypothesis

Educational guidelines are expected to positively affect mothers' practice and knowledge, as well as to lower their anxiety levels about their children's Ewing sarcoma.

### Research Setting

This study was applied in the Pediatric Outpatient Clinic for bone tumors at Sohag University Hospital in Egypt. It serves all citizens for all ages with cancer that live in Sohag governorate. Also, it worked all the week from 9A.m to 1P.M.

### Subjects

A convenient sample of 300 mothers was obtained from the previously selected settings within six months.

### Tools of the study

#### Three tools were used in the current study:

**Tool I: Mothers' knowledge regarding Ewing sarcoma,** it was developed by the researchers after reviewing the related literature (Saeed et al., 2021; Ahmed et al., 2023). It was used to assess the following two parts:

**Part 1: Personal data of mothers:** It contained the characteristics of the mothers under study, which included four items pertaining to residence, occupation, age, and educational attainment.

#### Part 2: Mothers' knowledge regarding Ewing sarcoma:

It was used to assess mothers' knowledge about Ewing sarcoma (pre and post) and comprised meaning, risk factors, symptoms, complications, drugs, drug precautions, and nutrition (Norberg et al., 2017).

A score of one (1) was given for each right response, and a score of zero (0) for each incorrect response. A score as a percentage was created from the overall scores. The total score for knowledge was divided into three categories: fair knowledge (51–70%), poor knowledge ( $\leq 50\%$ ), and good knowledge ( $\geq 71\%$ ). With a reliability value of Cronbach's alpha, the scale was deemed adequate.

#### Tool II: Mothers' reported practice regarding Ewing sarcoma:

It was developed by researchers after reviewing the related literature (Gargallo, et al., 2020). It was used to assess mothers' reported practices related to Ewing sarcoma. It includes 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).

#### Total reported practice scoring system

Mothers who checked the right answer on reported practice items received a score of (1), while those who checked the wrong response received a score of (0). The average score for the section is calculated by dividing the total number of items by the sum of item scores and totals for each stated practice domain. A total of 64 reported practice points were earned. A percentage was calculated from this data. If the total reported practice scores were good at least 65 percent (41 points), average if they were between 50 and 65 percent (32 and 41 points), or below 50 percent (32 points), they were deemed poor.

#### Tool III: Zung's self-rating anxiety questionnaire

Anxiety levels were measured using Zung's self-rating anxiety scale (Zung, 1971). There are 20 validated self-report questions in all. A four-point Likert scale is used as the instrument, with 1 denoting "never" or "very rare," 2 denoting "sometimes," 3 denoting "often," and 4 denoting "very often or always." Questions 1 through 5 described the emotional aspects of anxiety,

whereas questions 6 through 20 represent the physical aspects of anxiety. Scores for 20 elements add up to a total score between 20 and 80. Following that, the total scores were transformed into a "Anxiety Index" with values ranging from 25 to 100. This index was then interpreted as follows: moderate to moderately high anxiety levels (45–59), marked to severe anxiety levels (60–74), normal range (20–44), and extreme anxiety levels (75 and above). Cronbach's alpha for Internal consistency was .82 (Tanaka-Matsumi and Kameoka, 1986). Cronbach's alpha for the Statistical Analysis System (SAS) in this study was 0.84.

### **The procedure of data collection**

#### **Preparatory phase**

The researchers prepared the educational guidelines and developed the instruments for data collection by reviewing the existing and previous literature, including available textbooks, papers, magazines, and online searches. The dean of the nursing faculty sent a formal letter to the management of Sohag University Hospital before the study's commencement, asking for their cooperation and consent to collect data from the chosen location.

#### **Validity of the tools**

A board of five expert professors, including two professors of education, two professors of pediatric nursing, and one professor of community health nursing evaluated the tools' face and content validity for clarity, comprehensiveness, appropriateness, and relevance. The board determined the tools' face and content validity after they had more than ten years of experience in their respective fields. The instrument had an 89% content validity index (CVI).

#### **Reliability of the tools**

Cronbach's alpha reliability test was used to assess reliability;  $\alpha=85\%$  indicated high reliability for the first tool, which had relatively homogenous items;  $\alpha=82\%$  indicated reliability for the second tool; and  $\alpha=919$  indicated reliability for the third

tool. The instrument's reliability was assessed by comparing variables using the Pearson correlation coefficient test. The Pearson correlation coefficients for the variables ranged from  $P < 0.5$  to  $P < 0.001$ , suggesting a highly significant positive relationship between the variables of the subjects.

#### **A pilot study**

Following the tool's creation, a pilot study including 10% of the mothers was carried out on 30 mothers. It was not included in the entire sample. It was carried out to identify any ambiguities in the instruments, guarantee item transparency, and calculate the amount of time spent on data collecting. Based on the findings of the pilot study, the final version of the tools was developed by clarifying and evaluating the viability of the research method required for improvements.

#### **Ethical considerations**

This study was conducted with formal approval from the Dean of the University Faculty of Nursing, who issued a letter. An official permission to carry out the study was obtained from the ethical committee of the faculty of nursing. In the first section, the mothers explained the study's purpose. Before the questionnaire was administered, the researcher told the participants that participation in the study was entirely voluntary, that they had the option to decline, and that they could leave the study at any moment, for any reason. They were also promised that the information they provided would be kept private and utilized exclusively for study.

This study was implemented in three phases: assessment, implementation, and evaluation.

#### **Phase of preparation**

Based on the findings of the evaluation phase, the educational sessions' content was decided. Before being given to the nurses to use as a self-study guide, the

researchers prepared the instructional illustrated booklet and verified its content. The following procedures were followed to implement the educational guidelines for the research participants:

a. Outlining the program's aims and purposes

Goal: To evaluate the effect of educational guidelines on mothers' knowledge, practices, and anxiety regarding their children having Ewing sarcoma.

### Specific goals

When the sessions are over, the taught mother ought to be able to execute the following:

- Explain what Ewing sarcoma is.
- Describe the risk factors of the Ewing sarcoma.
- Enumerate the symptoms of the Ewing sarcoma.
- Explain the complications of the Ewing sarcoma.
- Be aware of drugs, drug precautions for the Ewing sarcoma.
- Describe feeding during for children with Ewing sarcoma.
- Demonstrate personal hygiene, nutrition, elimination, transferring, drug administration, pain management, and sleep for children having Ewing sarcoma.
- Describe relevant strategies for managing anxiety.

### Phase of implementation

The hospital lecture hall was used to offer the educational sessions. Lectures, group discussions, and brainstorming were among the many teaching techniques used. To help assist and make instructions clear, laptop data was shown in graphics and videos during the sessions. An overview of the previous session's content is given at the start of each one, and then the goals of the session are discussed to make sure moms understand the information. Four sessions, each lasting 30 to 45 minutes and including discussion intervals, made up the program. The post-test was given right

away, and each session involved seven to nine mothers every day.

The first session began with the mothers being greeted and given an introduction by the researchers. The goal of the session is stated, along with the significance of the subject, its substance, and its duration, meaning, risk factors, symptoms, complications, drugs, drug precautions and feeding that researchers shared. In later sessions, the researchers showed personal hygiene, nutrition, elimination, transferring, drug administration, pain management, and sleep.

Instruction on future anxiety (definition, signs, and symptoms, Some strategies for managing anxiety include having healthy daily routines, communicating effectively with others, managing negative thoughts, and asking for and receiving support from friends, family, and others to increase one's sense of security. It covered anxiety-reduction strategies like explaining meditation (definition, steps), the value of deep breathing, muscle relaxation, yoga, and the role of nurses in the Ewing sarcoma to the mothers in the study.

After every session, participants reviewed the goals of the new topics and offered input on the previous one. A PowerPoint presentation accompanied this, and the contents were discussed in a group setting. Through comments, the researchers also assisted mothers in gaining knowledge and practice. As a reference to be used following the intervention, pamphlets with eye-catching pictures and straightforward, uncomplicated text were also supplied in a booklet.

### Phase of evaluation

Using the same pre-assessment tools, the effect of educational guidelines on mothers' knowledge, practices, and anxiety regarding their children having Ewing sarcoma was re-assessed post one month to ensure its effectiveness.

### Statistical analysis

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The Statistical Package for Social Sciences (SPSS) version 25 was used to analyze the data. Using the mean and standard deviation for the participant's age, descriptive data was displayed in frequency and percentage for the demographic data. Using Pearson's Chi-square test ( $\chi^2$ ), the Monte Carlo exact test, and the Fisher exact test (FET), the participants' knowledge, practices, and anxiety level of the tool were compared across the four colleges. Additionally, the ANOVA test of significance was used to examine the association. The correlations were examined using the Pearson coefficient (r) test. With a significance threshold of 5%,  $p \leq 0.05$  was deemed significant.

### Results

**Table 1** displays the personal data of the mothers under study. The mothers in the study were found to be between the ages of 20 and 30 (54%) with an average age of  $28.4 \pm 2.5$  years. In terms of education, 80% of mothers were housewives, 75% lived in urban areas, and (46%) of them were illiterate.

According to 75% of the mothers in the study, doctors were their primary source of information on Ewing sarcoma, as seen in **Figure 1**.

**Table (2)** demonstrated that the mothers had significantly different levels of knowledge about Ewing sarcoma before and after the implementation of educational guidelines (P value:  $<0.001$ ). Before the implementation of the educational guidelines, the mothers' mean score was  $7.4 \pm 1.1$ , and after the implementation of the guidelines, it rose to  $27.4 \pm 1.5$ , with highly significant differences (P-value:  $<0.001$ ).

**Figure 2** demonstrated that, before the introduction of educational guidelines, the majority of mothers (94%) had poor information regarding Ewing sarcoma, however, following the implementation of educational guidelines, 90% of them had good knowledge.

**Table 3** showed that, following educational guidelines, mothers' reported practices regarding Ewing sarcoma improved in all examined areas and showed highly statistically significant differences ( $P < 0.001$ ).

**Figure (3)** made it clear that 90% of the mothers in the study had poor Ewing sarcoma practices prior to the introduction of educational guidelines, and a month later, their rates dropped. In contrast, 85% of the mothers in the study had good practices regarding the implementation of educational guidelines about Ewing sarcoma, but none of them had good practices regarding the implementation of educational guidelines before.

**Table (4)** demonstrates that, with differences that are highly statistically significant ( $P < 0.001$ ), the overall mean score of the mothers' anxiety about Ewing sarcoma was lower after the educational guidelines than before. There were very statistically significant differences in the overall mean anxiety score, which was  $69.84 \pm 7.8$  before educational guidelines and  $35.5 \pm 6.4$  after them ( $P < 0.001$ ).

Following the educational guidelines, the women in the study showed a decrease in their overall level of anxiety (**Figure 4**). It was shown that only 40% of the mothers had moderate anxiety levels in the study and no one had severe moderate anxiety levels after the educational guidelines, whereas 65% of them had severe anxiety levels before.

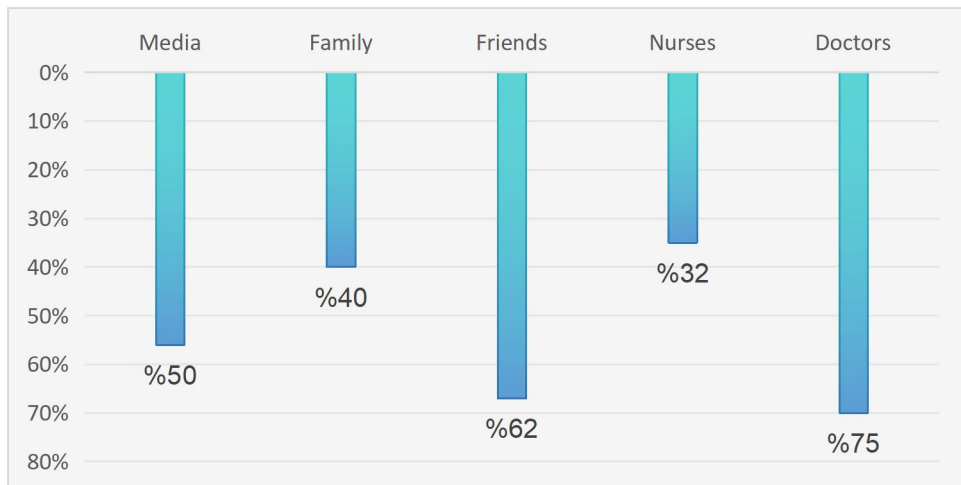
**Table (5)** shows that there was a moderately negative association between the mothers' level of education and their knowledge (P value  $< 0.001$ ), as well as between the mothers' level of anxiety and residence (P value  $< 0.001$ ).

**Table 6:** The knowledge and anxiety of the mothers under study about the post-educational guidelines for Ewing sarcoma were found to be moderately negatively correlated.



**Table (1): Personal Data among the Studied Mothers (n=300)**

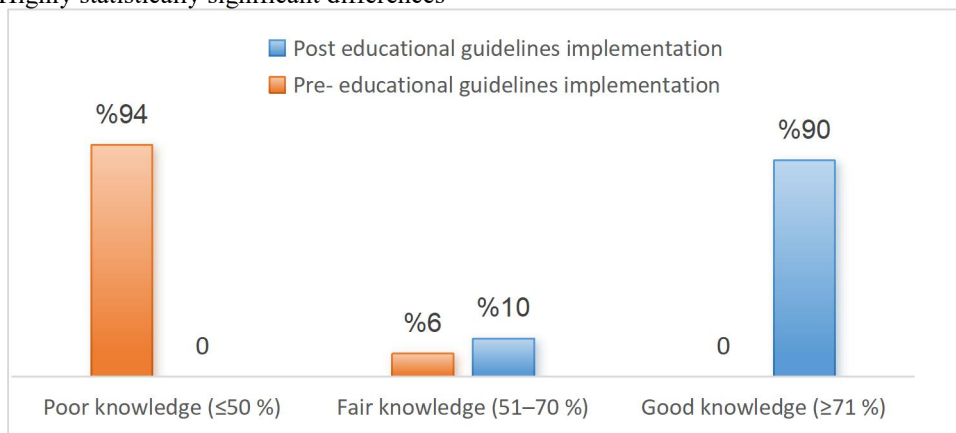
Personal data	No.	%
<b>Age(years)</b>		
20 < 30	162	54.0
30 - 35	90	30.0
35 ≥40	48	16.0
<b>Mean and SD</b>	<b>(28.4±2.5)</b>	
<b>Educational level</b>		
Illiterate	138	46.00
Secondary education	84	28.00
Bachelor's degree	78	26.00
<b>Occupation</b>		
Housewives	240	80.00
Working	60	20.00
<b>Residence</b>		
Urban	225	75.00
Rural	75	25.00

**Figure (1): Source of Knowledge regarding Ewing sarcoma among the Studied Mothers (n=300)**

**Table (2): Total Mean Scores' Knowledge among the Studied Mothers about Ewing sarcoma and Pre/ Post educational guidelines (n=300)**

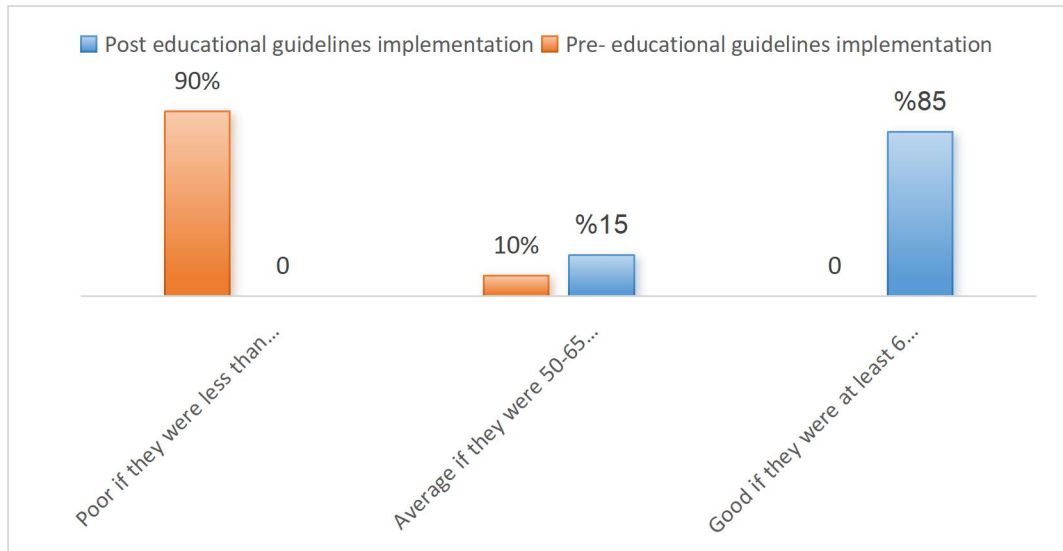
Items	Pre educational guidelines	Post educational guidelines	t-test	P-value
<b>Total knowledge scores</b>	7.4 ± 1.1	27.4 ± 1.5	33.12	0.0001**

\*\*Highly statistically significant differences

**Figure (2): Total Mothers' Knowledge Level regarding Ewing sarcoma pre- post educational guidelines implementation (n=300)****Table (3): Mothers' Reported practices distribution regarding Ewing sarcoma Pre/ Post educational guidelines implementation (n=300)**

Preventive measures	Pre educational guidelines	Post educational guidelines	t-test	P-value
Personal hygiene	45(15.0)	270(90.0)	23.4	<0.001*
Nutrition	54(18.0)	240(80.0)	42.3	<0.001*
Elimination	24(8.0)	198(66.0)	31.8	<0.001*
Transferring	51(17.0)	276(92.0)	35.7	<0.001*
Drug administration	48(16.0)	264(88.0)	28.3	<0.001*
Pain management	60(20.0)	258(86.0)	37.8	<0.001*
Sleep	30(10.0)	210(70.0)	31.7	<0.001*

\*Significance at 0.001 levels

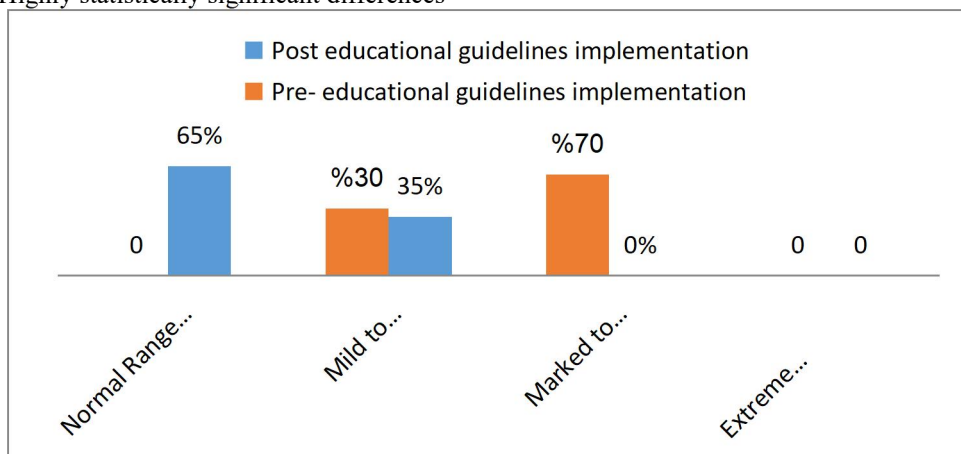


**Figure (3): Mothers' Total Reported Practice Level regarding Ewing sarcoma Pre- and Post-educational guidelines implementation (N= 300).**

**Table (4): Total Mean Scores of Anxiety level among the Studied Mothers regarding Ewing sarcoma Pre and Post educational guidelines (n=300)**

Anxiety items	Pre educational guidelines	Post educational guidelines	t-test	P-value
Total anxiety	69.84 ± 7.8	35.5 ± 6.4	18.45	0.001**

\*\*Highly statistically significant differences



**Figure (4): Total Anxiety level regarding Ewing sarcoma among the Studied Mothers pre- and post-educational guidelines (n=300)**

**Table 5: The correlation between the mothers' selected personal data and their total knowledge, reported practices, and anxiety level (n= 300).**

Items		Knowledge	Practices	Anxiety level
Age	R	-.126-	-.103-	.192
	P – value	.353	.462	.187
Educational level	R	<b>-.563</b>	.025	-.042-
	P – value	<b>.001**</b>	.865	.759
Occupation	R	.081	<b>-.355</b>	<b>-.362</b>
	P – value	.623	<b>.017*</b>	<b>.007**</b>
Residence	R	.046	<b>-.276</b>	<b>-.523</b>
	P – value	.741	<b>.028*</b>	<b>.001**</b>

\*\* . Correlation is significant at the 0.01 level.

**Table (6): Correlation between Total Knowledge, reported practice, and Anxiety among the Studied Mothers regarding Ewing sarcoma pre- and post-educational guidelines (n= 200).**

Items	Variables		Pre- educational guidelines	Post-educational guidelines
			Knowledge	Knowledge
Pre- educational guidelines	Practices	R	-0.100	0.014
		P – value	0.465	0.953
	Anxiety level	R	-0.087	0.172
		P – value	0.539	0.234
Post-educational guidelines	Practices	R	0.179	-0.556
		P – value	0.559	0.014*
	Anxiety level	R	0.868	-0.664
		P – value	0.187	0.015*

\*. Correlation is significant at the 0.05 level.

## 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). Hence, the study was done to determine the effect of educational guidelines on mothers' knowledge, practices, and anxiety regarding their children having Ewing sarcoma.

Regarding personal data of the studied mothers, the present study revealed that more than half of the studied caregivers their age ranged between 20 and 30 with an average age of  $28.4 \pm 2.5$  years. In terms of education, the majority of them were housewives, three quarters lived in urban areas, and more than two thirds of them were illiterate. From the researchers' point of view, it reflected the cause of knowledge deficit. More psychological problems, like worry, may have been caused by the mothers in the study because they were too young and lacked sufficient information.

According to three quarters of the mothers studied, the doctors were their primary source of information on Ewing sarcoma. From the researcher's perspective, this demonstrated that mothers look to the appropriate place for assistance. About total knowledge of the studied mothers regarding Ewing sarcoma, the present study demonstrated that the mothers had significantly different levels of knowledge about Ewing sarcoma before and after the implementation of educational guidelines. 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.

The current study demonstrated that, before the introduction of educational guidelines, the majority of mothers had poor information regarding Ewing sarcoma, however, following the implementation of educational guidelines, most of them had good knowledge. According to the study, this demonstrated the need to implement educational guidelines for mothers to enhance their knowledge. These findings was in the same line with a study in United kingdom conducted by Makhoul 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' knowledge about care were low.

The present study showed that, following educational guidelines, mothers' reported practices regarding Ewing sarcoma improved in all examined areas and showed highly statistically significant differences. From the researchers' point of view, it confirmed the positive effect of educational guidelines that help in enhancing mothers' knowledge and associated with improving their practice.

The current study revealed that most of the mothers in the study had poor Ewing sarcoma practices before the introduction of educational guidelines. In contrast, the majority of the mothers in the study had good practices regarding the implementation of educational guidelines about Ewing sarcoma, but none of them had good practices regarding the implementation of educational guidelines. 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 and mentioned that most of the studied mothers had low level of competence regarding care before intervention.

This result validated Fan et al.'s (2020) "theory of KAP," which states that a change in health behavior results from practicing and

possessing the appropriate information. Additionally, a recent study by **Rana et al. (2020)** discovered a connection between successful illness prevention, control, and promotion and enough personal knowledge. According to a study by **Ricardo et al. (2018)**, bad health and maladaptive disease prevention behavior are associated with a lack of knowledge.

The current study pointed that there were highly statistically significant differences in the overall mean score of the mothers' anxiety about Ewing sarcoma were lower after the educational guidelines than before. This may be because mothers are not familiar with the issue and are concerned about potential consequences for their children in the event that they get sick, the researchers believe.

The current study shows that the mothers' educational level and their knowledge had a moderately negative link. Mothers' occupation, residence, and anxiety levels also showed a moderately unfavorable association. High mean scores of mothers' anxiety is associated with pre-educational guidelines of the mothers under investigation, especially in rural areas. This could explain why mothers in rural areas are more stressed due to a lack of medical protective supplies, a lack of awareness from social media, and the difficulty of traveling to an urban health center or hospital when their children exhibit symptoms of infection. Additionally, rural and urban areas have different cultures, values, and beliefs. Moreover, mothers' high levels of anxiety were connected to their work. This result could be due to working mothers leaving their young children unattended for long periods while at work, increasing their anxiety for their children who are left alone.

According to these findings, mothers who followed the educational guidelines had lower levels of overall anxiety. According to the researcher, it demonstrated the accomplishment of the study's goal and the importance of putting educational recommendations into practice that lead to improvements and a decrease in anxiety levels. These results may be explained by the dearth of medical facilities in the nation as well as mothers' anxiety about their children being

sick. Mothers may feel emotionally distressed by their children at home, especially if they become ill (**Kohi et al., 2019**).

Following the educational guidelines, the women in the study showed a decrease in their overall level of anxiety. It was shown that two thirds of the mothers had moderate anxiety levels in the study and no one had severe had moderate anxiety levels after the educational guidelines, whereas less than three thirds of them had severe anxiety levels before.

In the view of the researchers, this might be because of the success of adhering to the educational guidelines, which led to learning more and experiencing less anxiety since they now understand the primary causes of anxiety and have alternative strategies for handling these emotions. Additionally, participants learned how to relax and cope with pressures in uncomfortable situations. They also learned that accepting unforeseen life events is essential to managing anxiety.

Regarding the relationship between personal data of the studied mothers' and their total knowledge and practices regarding Ewing Sarcoma, the current study indicated that there was a moderately negative association between the mothers' level of education and their knowledge, as well as between the mothers' level of anxiety and residence.

This can be interpreted as older mothers and those who have higher levels of education are more likely to have satisfactory level of knowledge than others. 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", 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)** found that there were no statistically significant relationships between the total mean scores of mothers' knowledge and their personal data as age and level of education.

This can be explained as mothers who are older, females, with high level of education are more likely to have good level of practice than others. These results were supported by a study conducted by **Khademi et al., (2019)** who

asserted that variables of age and educational level, 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", and found that all demographic characteristics of the mother were not associated with the mothers' level of practice.

The current study result revealed that the knowledge and anxiety of the mothers under study about the post-educational guidelines for Ewing sarcoma were found to be moderately negatively correlated. This can be explained as the more the caregivers have knowledge the more, they are competent and have good practice. This contrast, **Saeed et al., (2021)**, they stated that there wasn't a relation between mothers' knowledge and practice. 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.

### Conclusion

Based on the current study's findings, the researchers concluded that according to the study's findings, mothers' knowledge, reported practice, and anxiety levels are all improved when educational guidelines about Ewing Sarcoma are implemented.

### Recommendations

**Based on the current study's findings, the following suggestions were made:**

- To support psychological adaptation, it is essential to provide mothers with a comprehensive health education program that improves their knowledge of Ewing Sarcoma and strengthens their engagement in appropriate interventions.
- Conducting educational programs periodically and regularly for children and their mothers to improve their knowledge and practices regarding Ewing sarcoma disease.
- Ensure that the outpatient clinics of bone tumors are equipped with accessible written and visual educational materials about Ewing Sarcoma, such as brochures

and booklets to aid in informing both children and their mothers about the condition.

- Availability of relevant written and visual information in Ewing sarcoma outpatient's clinic to facilitate the education of children and their mothers about Ewing sarcoma disease such as educational booklets and brochures.
- Further studies including larger sample size of children with Ewing sarcoma and their mothers from different geographical areas to generalize the results in Egypt.

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