

Parental Emotional Resilience and Procedural Anxiety of their Children with Cancer

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Abstract

Background: Childhood cancer is a challenging, stressful and unpredictable experience for children and their parents. Since children diagnosis with cancer and throughout treatment journey, they may undergo painful invasive procedures, which heightens their procedural anxiety. Moreover, caring for cancer children may negatively affect parental physical and psychological well-being. **Aim:** To assess parental emotional resilience and procedural anxiety of their children with cancer in Ismailia governorate. **Design:** A descriptive research design was used to achieve the aim of the study. **Sample:** A purposeful sample of one hundred and thirty-eight child suffering from cancer and undergoing treatment procedures aged 8-12 years old and one parent (mother or father) for each child. **Tools for data collection:** The data were gathered through structured interview where the tools divided into two parts: The first part includes demographic characteristics of the studied subjects and the second part includes two adopted tools; the Nicholson McBride Resilience Questionnaire and the Pediatric Quality of Life Inventory cancer Module. **Results:** Most of parents of children with cancer in this study have low levels of parental emotional resilience. Moreover, the majority of studied cancer children have high level of procedural anxiety. **Conclusion:** Parents of children with cancer are at substantial risk for poor emotional resilience, while their cancer children are at greater risk for procedural anxiety. **Recommendation:** Inclusion of pediatric psycho-oncology nursing in the professional structure of health care in Egypt and maximizing its role as a cornerstone in the success of the multi-faceted management process.

Key words: Childhood cancer , Children, Emotional resilience, Parents, Procedural anxiety.

1. Introduction

Egypt ranks the second in the number of childhood cancer cases in the Eastern Mediterranean region (*Soliman et al., 2021*). Moreover, it is difficult to estimate the incidence rate of childhood cancer in Egypt due to the

absence of a national cancer registry. The Children's Cancer Hospital in Egypt (57357) is the largest cancer hospital in the country, annually enrolling approximately 3000 patients younger than 18 years, its estimated that this number represents 50% of childhood cancer cases in a

country with a population of around 100,000,000 (*Basbous et al., 2021*).

Concerning children with cancer, despite the complexities of their cancer treatment journey, which includes numerous challenges such as multiple hospitalizations, adverse physical and psychological side effects of various treatment modalities. However, pain remains the most difficult challenge for children with cancer (*Tennant et al., 2022*).

Across the cancer continuum, pain is a prevalent, repetitive and impactful symptom. The prevalence of pain in children during the active period of cancer treatment varies from 28% to 62%, with >50% of children with cancer reporting that pain intensity range from moderate to severe (*Rheel, Heathcote, van der Werff, Schulte & Pate, 2022*).

Children with cancer report that the painful invasive procedures such as blood tests, intramuscular injection, lumbar puncture, bone marrow aspiration and biopsy are the main source of fear and anxiety during cancer treatment journey (*Aslan & Erci, 2022*).

Furthermore, frequent procedural pain in conjunction with the limited language and coping abilities of children with cancer may result in aggravating emotional outcomes for children such as procedural anxiety (*Tillery, Willard, Long, & Phipps, 2019*).

Regarding the term procedural anxiety, it relates to an affective state of anxiety or fear which associated with painful medical procedures.

It is associated with acute distress and may result in behavioral disruptions such as avoiding or terminating of medical procedures (*Forbes et al., 2020*).

Procedural anxiety is not only annoying for children with cancer but also for their parents and may render the treatment process of children with cancer more complicated (*Alabbas et al., 2022*). Additionally, a child's procedural anxiety may interfere with necessary medical procedures (*Fischmeister et al., 2021*). So, procedural anxiety may represent an obstacle against achieving successful treatment outcomes for children with cancer (*Acosta et al., 2022*).

Here, comes the crucial role that parental emotional resilience may play in improving parental adjustment to their children's cancer and its related issues by fostering their innate strengths (*Luo et al., 2022*). Moreover, emotional resilience helps parents of children with cancer in overcoming the diagnosis crisis, lessens the effect of the tasks entailed by medical care and treatment (*Toledano-Toledano et al., 2021*).

Also, emotional resilience may help parents in preparing and supporting their children with cancer before and during painful invasive medical procedures such as blood withdrawal and it may play a vital role in reducing anxiety, stress, adverse behavioral and physiological symptoms of children with cancer (*Sağlık & Çağlar, 2019*).

Liaison psychiatric nurses may play an indispensable role in caring for children with

cancer. They not only provide technical and scientific knowledge, but also give humanized care to promote the health, quality of life, comfort and well-being of children with cancer (*Nukpezah, Khoshnavay, Hasanpour & Nasrabadi, 2021*). Moreover, they play an vital roles in providing emotional, social, educational and physical support for parents of children with cancer as a primary caregivers for their children (*Bradley, 2019*).

1.1. Significance of the study:

Childhood cancer is a chronic disease that affects physical, mental, social and behavioral spheres of the lives of 397 000 children each year worldwide in addition to their parents and it is estimated that 85% of these cases occur in low and middle-income countries (*Cotache-Condor et al., 2022*).

Moreover, 50–70% of children experience severe procedural anxiety as a strong negative reaction to the painful medical procedures. Procedural anxiety may be considered as a child's response to a potentially traumatic event (*Brown, De Young, Kimble & Kenardy, 2018*).

Furthermore, childhood cancer requires continuous care through treatment, hospitalization and coping with the side effects of therapy. It impacts the quality of life of the parents of children with cancer as a primary family caregiver on a personal, social, and professional level and increases their

susceptibility to related emotional and physical disorders (*Lewandowska, 2022*).

Parental emotional resilience may be a key factor behind effective parental coping with their children cancer and its related problems. As a personal characteristic, resilience relieves parents' discomfort, improves quality of life, promotes positive adaptation, moderates the negative effects of stress, empowers individuals to protect their health and in turn improve psychosocial well-being and life satisfaction of their children with cancer (*Habibpour et al., 2019*).

Therefore, liaison psychiatric nurses can play a key role in holistic and palliative care for children with cancer. Pediatric palliative care aims to assess, manage physical and psychological symptoms, decrease suffering and enhance the quality of life. In addition, provide support for children with cancer and their parents throughout the course of childhood cancer treatment (*Snaman, McCarthy, Wiener & Wolfe, 2020*).

The aim of the study:

The aim of the present study was to assess parental emotional resilience and procedural anxiety of their children with cancer in Ismailia governorate.

Objectives:

- 1- Assess emotional resilience of parents whose children suffering from cancer and

undergoing treatment procedures.

- 2- Determine procedural anxiety levels of children suffering from cancer and undergoing treatment procedure.
- 3- Assess the relationship between parental emotional resilience and procedural anxiety of their children with cancer.

2. Subject and Methods

Study design: a descriptive research design was used to achieve the aim of the study.

The sample of the study:

One hundred and Thirty-eight (138) child with cancer and undergoing treatment procedure aged 8-12 years old and one parent (mother or father) for each child from previously mentioned settings..

Study setting: The present study conducted at Pediatric Hematology and Oncology outpatient Clinics at two hospitals in Ismailia governorate, namely:

- 1- Suez canal university hospital.
- 2- Ismailia oncology teaching hospital.

Tools of data collection:

Tool I: Child and parent demographic data questionnaire which includes data such as (age of child and parent, sex of child and parent, diagnosis of child, duration of cancer, rank of child in the family, marital status of parents, level of education and occupation of parentsetc).

Tool II :The Nicholson McBride Resilience Questionnaire (NMRO) which developed by (Clarke & McBride ,2010) and translated into Arabic by the researcher. It consists from a 12-items such as (I am calm in a crisis and I manage my stress levels well) which designed for measuring levels of resilience through four levels (developing resilience, established resilience, strong resilience and exceptional resilience). Each item is measured through a 5-Likert scale point system. The scoring scheme is between 1 and 5, with 1= strongly disagree and 5= strongly agree.

Tool III: The Pediatric Quality of Life Inventory (PedsQL) cancer Module Version 3.0 (Child and Parent Model for Children ages 8-12). It was developed by (Varni et al.,2002) and translated into Arabic by the researcher to assess procedural anxiety and other related dimensions of health related quality of life which specifically tailored for childhood cancer. It consist of 27 items grouped into eight subscales. Procedural anxiety subscale (3items, i.e. I get scared when I have to have blood tests), pain and hurt subscale (two items, i.e. I ache or hurt in my joints and/or muscles), nausea subscale (five items, i.e. I become sick to my stomach when I have medical treatments), treatment anxiety subscale (three items, i.e. I get scared when I have to go to the hospital), worry subscale (three items, i.e. I worry about side effects from medical treatments), cognitive

problems subscale (five items, i.e. It is hard for me to pay attention to things), perceived physical appearance subscale (three items, i.e. I feel I am not good looking) and communication subscale (three items, i.e. It is hard for me to tell the doctors and nurses how I feel). Each item is measured through a 5-point Likert scale ranging from 0 to 4 in which 0 = never a problem and 4= almost always a problem.

Fieldwork:

Data were collected within ten months from the end of October 2021 up to the end of July 2022. Data were collected four days per week from the previously mentioned settings by rotation from 9 am to 2 pm. The interview with children and their parents were held in waiting areas for children and their parents which located in front of the outpatient clinics of the previously mentioned settings.

Pilot study: A pilot study carried out after the development of the tools and before starting the data collection, it applied on 10% of subjects, 13 child who suffering from cancer and undergoing treatment procedures and their 13 parents who suffering from cancer and undergoing treatment procedures to test applicability, clarity, feasibility and relevance of the tools.

Ethical considerations:

Primary approval obtained from the

research ethical committee in the Faculty of Nursing, Suez Canal University. The researcher explained the aim and nature of the study to children and their parents for gaining their cooperation. Oral affirmative consent obtained from children while written consent was obtained from their parents to participate in the study and inform them about voluntary participation and about their right to withdraw at any time from the study. The topic of this study did not touch religious, ethical, moral and culture issues.

Administrative design:-

An official permission was obtained using proper channels to seek the permission for carrying out the study. The researcher gave extensive explanation to the director of selected setting about the aim, importance and nature of the study to obtain their permission and cooperation to execute the practical aspect of the study in the previously mentioned settings.

Statistical design:

Upon completion of data collection, variables which included in each data collection sheet were organized and tabulated then coded prior to computerized data entry. The data were then imported into statistical package for social sciences (SPSS version 20.0) software for statistical analysis, mean, stander deviation, independent sample T test, one way ANOVA test and person correlation coefficient test were used in the study

3. Results

Table (1) shows that the mean age of cancer children was 9.83 ± 1.63 . Male children constituted more than half of the sample (57.25%) and slightly more than half of children (52.90%) were first in birth rank. leukemia was the most common type of cancer among studied children (43.48%). the majority of children (84.06%) had cancer since ≤ 1 year.

Figure (1) reveals that, nearly two thirds of studied parents (64.49%) had a developing level of emotional resilience. While, 18.84% of them had intermediate level of emotional resilience. On other hand, only 16.67% of them had a strong level of emotional resilience and no one (0.00%) of them had an exceptional level of emotional resilience.

Figure (2) shows that, almost three quarters of children had a high level of procedural anxiety (73.91%). While, less than one quarter of them had intermediate level (23.19%). On other hand, the minority of them had a low level of procedural anxiety (2.90%) as reported by children.

Figure (3) shows that, 76.81% of children had a high level of procedural anxiety.. While, 22.47% of them had intermediate level of procedural anxiety. On the other hand, only 0.72 % of them had low level of procedural anxiety as reported by their parents.

Table (2) shows that there was a highly statistically significant relation between levels of parental emotional resilience and total procedural

anxiety of their children whereas $p < 0.001$. It is evident that the level of children's procedural anxiety increased with lower levels of parental emotional resilience.

Table (3) demonstrates that the age of children was a highly statistically significant independent positive predictor of their procedural anxiety ($p=.000$) in which older age is associated with lower levels of procedural anxiety. Moreover, parental emotional resilience was a highly statistically significant independent positive predictor of their children's procedural anxiety ($p=.000$) in which a higher level of parental emotional resilience was associated with lower levels of their children's procedural anxiety.

4. Discussion

Childhood cancer and its treatment journey are not only a stressful experiences for children with cancer, but also they disrupt their parents' daily lives, especially during the first year after diagnosis, which may be described as the most stressful period of the parents' lives (*Cheung et al., 2021*). Parents of cancer children may experience a combination of psychological, mental and physical exhaustion, which may impair their ability to deal with new stressors that associated with their children's cancer and related issues (*van Warmerdam et al., 2019*).

The results of current study revealed that the majority of the studied parents had lower levels of emotional resilience. This result might be because the diagnosis of child with cancer and its

treatment journey may be associated with huge challenges and crisis beyond parents' control. The prior result was in agreement with **Dąbrowska and Malicka, (2022)**; **Luo et al., (2021)** who showed that the majority of parents of cancer children had low level of emotional resilience.

Incongruent with prior finding, a study conducted in Egypt at 57357 Hospital by **Mustafa, El-Ashry and Mahmoud, (2019)** revealed that half of the parents of cancer children had moderate level of emotional resilience. This may be attributed to multiple reasons such as proper emotional support provided from the social services team in the hospital, financial stability for some parents, enhancing of parental knowledge through health education which provided by nurses, interaction with parents having a child with the same diagnosis and finally.

The present study findings revealed that, the majority of cancer children had high level of procedural anxiety as reported by participated children and parents in this study. This high level of procedural anxiety among cancer children might be associated with multiple causes such as hurts which resulted from invasive medical procedures that include using of needles stick, being scared about having blood tests and being scared about undergoing painful medical procedures such as different types of injections.

In the same line with the current study finding, **Ocak et al, (2021)** revealed that cancer children who undergoing painful medical

procedure experience a real suffering with procedural anxiety. In this respect, **Barrera et al, (2020)** reported that cancer children with cancer had a real struggles with procedural anxiety throughout their treatment journey that is characterized by frequent painful medical procedures.

The result of the current study suggested that parental emotional resilience was a positive predictor of procedural anxiety among their cancer children, in which higher level of parental emotional resilience was associated with lower level of procedural anxiety of their cancer children. So, there was a highly statistically significant relation between parental emotional resilience and procedural anxiety of their cancer children.

The prior result is in agreement with **Luo et al., (2022)** who revealed that higher levels of parental emotional resilience was associated with lower levels of procedural anxiety of their cancer children.

Consistently, **Isokääntä, Koivula, Honkalampi and Kokki, (2019)** ; **Uhl, Burns, Hale and Coakley, (2020)** revealed that parental emotional resilience may play a vital role in alleviating procedural anxiety in cancer children because parental emotional resilience may help children with cancer to adjust with their illness and its associated issues such as anxiety which associated with painful medical procedures.

5. Conclusion:

Based on the results of the current study, it can be concluded that the majority of parents of cancer children in this study had lower levels of parental emotional resilience (Developing level of emotional resilience). On the other side, the majority of cancer children also experienced high levels of procedural anxiety. Furthermore, low levels of parental emotional resilience was associated with a high level of their children procedural anxiety.

6. Recommendations:

- Develop a variety of age-appropriate materials such as brochures, flyers, pictures and story where by simplified information about childhood cancer and ways of dealing with its related issues can be presented to children and their parents by the medical team of Pediatric Hematology and Oncology outpatient Clinics at Suez canal university hospital and Ismailia oncology teaching hospital;
- Create supporting groups for parents of children with cancer by specialists of

psychiatric medicine departments at Suez canal university hospital and Ismailia oncology teaching hospital, where parents have an opportunity to find mutual support and share their experiences and feelings through joining others who have a similar situations;

- Encouraging the nursing staff to participate in training programs that revolve around how to communicate freely and honestly with children with cancer and their parents in a therapeutic manner appropriate for their different age stages;
- Further studies is recommended on the psychological struggles which experienced by cancer children and their parents in Egypt, as well as the potential contribution of parental emotional resilience in coping with these struggles and preventing the escalation of psychological issues.

Table 1: Demographic characteristics of studied cancer children (n=138).

Children characteristics	Frequency	Percentage
Age (in years):		
8: <10 years	82	59.42
10:12 years	56	40.58
Range		8:12
Mean ± SD		9.83 ±1.63
Median		9.0

Gender:		
Male	79	57.25
Female	59	42.75
Birth Order:		
First	73	52.90
Second	45	32.61
Third or more	20	14.49
Types of cancer		
Leukemia	60	43.48
Stomach cancer	21	15.22
Lymphatic cancer	12	8.70%
Left hip cancer	10	7.25%
Others	35	17.38
Duration of cancer		
≤ 1 year	116	84.06
> 1 year	22	15.94

Figure 1: Levels of emotional resilience among studied parents of cancer children (n=138).

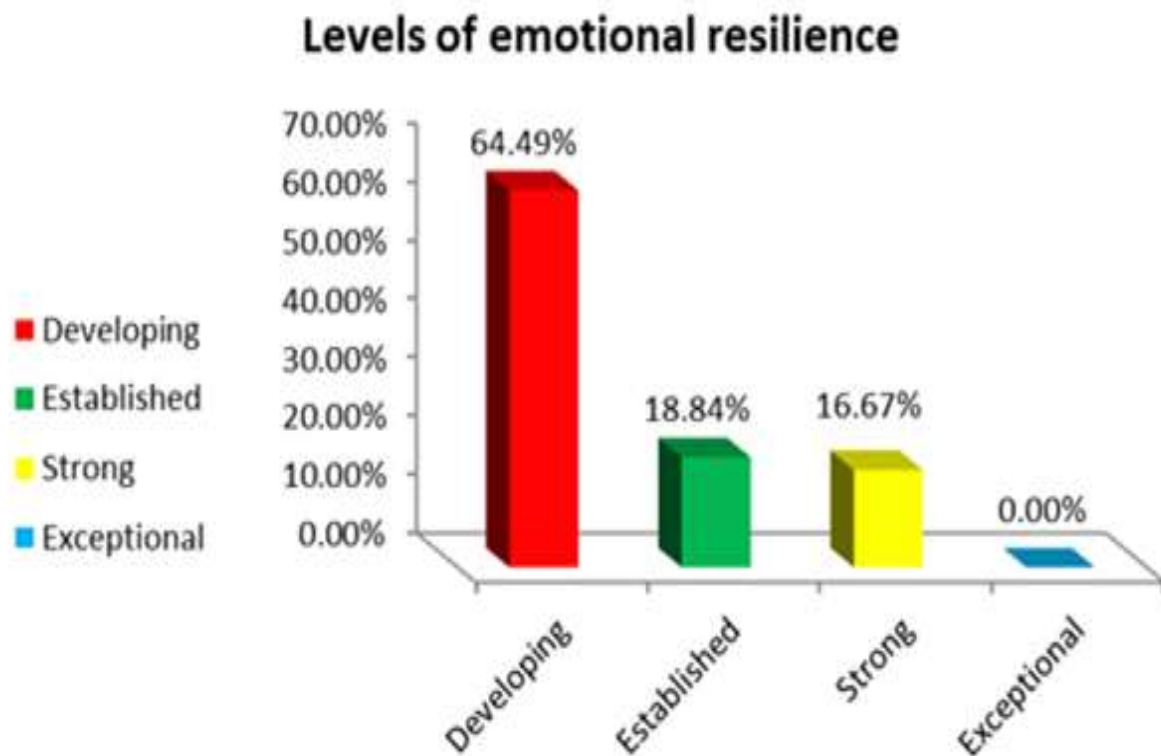


Figure 2: levels of procedural anxiety among studied cancer children according to Pediatric Quality of Life Inventory (child model) (n=138).

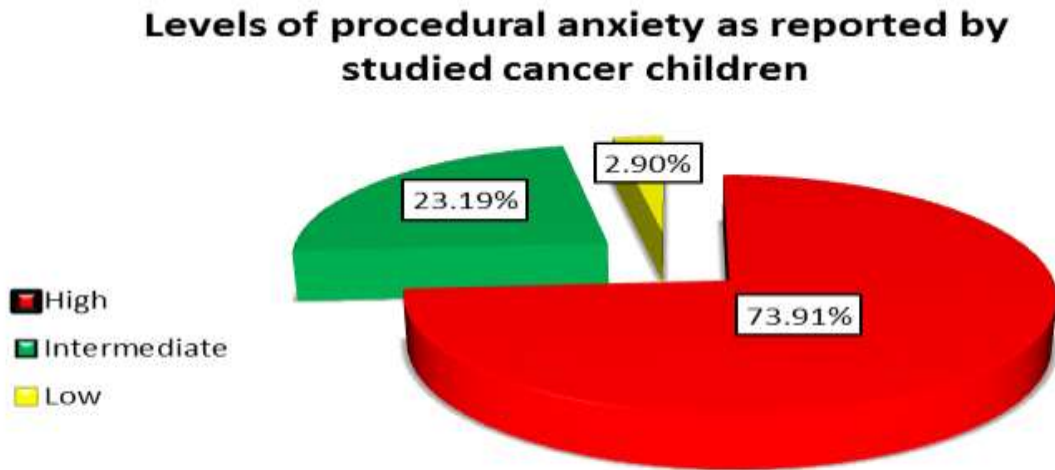


Figure 3: levels of procedural anxiety among studied cancer children according to Pediatric Quality of Life Inventory (parent model) (n=138).

Levels of procedural anxiety among children as reported by their parents

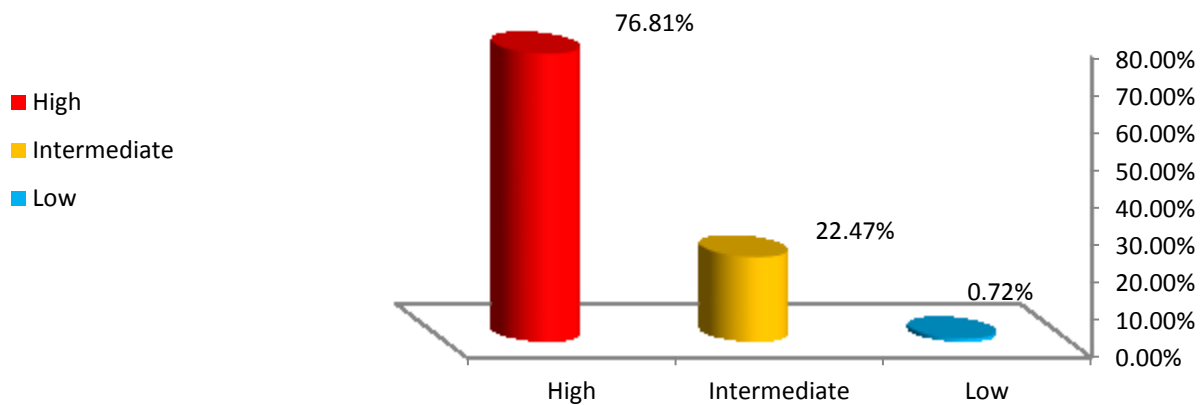


Table 2: Relation between parental emotional resilience levels and procedural anxiety of their children according to Pediatric Quality of Life Inventory (child model) (n=138).

Levels of Parental Emotional Resilience	Levels of procedural anxiety of children as reported by them						F test	P value
	Low level of procedural anxiety		Intermediate Level of procedural anxiety		High Level of procedural anxiety			
	No.	%.	No.	%.	No.	%.		
Developing level of emotional resilience	1	0.72	6	4.35	82	59.42	1.863	0.053
Established level of emotional resilience	1	0.72	11	7.97	14	10.14	.869	0.534
Strong level of emotional resilience	2	1.45	15	10.87	6	4.35	3.304	0.043*
Total	4	2.90	32	23.19	102	73.91	6.018	0.000**

P: p value for association between different categories

***Significant at P ≤ 0.05**

**** Highly significant at p < 0.001**

Table 3: Best fitting multiple linear regression model for children's procedural anxiety total score (child and parent model).

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