

## Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia

<sup>1</sup> Abd-Elmassih Nasry Yacoub, <sup>2</sup> Naglaa Fathi Mohamed EL-attar and <sup>3</sup>Doha Abd-Elbassir Mahmoud

(1) Demonstrator of Psychiatric and Mental Health Nursing, Faculty of Nursing, Sohage University, Sohage, Egypt, (2) Assistant Professor of Psychiatric and Mental Health Nursing, Faculty of Nursing, Benha University, Benha, Egypt and (3) Lecturer of Psychiatric and Mental Health Nursing, Faculty of Nursing, Benha University, Benha, Egypt.

### Abstract

**Background:** A diagnosis of childhood leukemia is a devastating experience for any parent, which cause parental stress and it has been shown to inflict a significant negative impact on their quality of life. **Aim of the study:** This study aimed to examine the relationship between parental stress and quality of life among parents of children with leukemia. **Research Design:** A descriptive design was utilized in this study. **Setting:** The study was conducted at hematology and oncology clinic at specialized Pediatric hospital in Benha city, Kaluobia Governorate and 57357 hospital for pediatric oncology. **Sample:** A purposive sample consisting of 100 parents of children with leukemia. **Tools:** In this study three tools were used for data collection: I) A structured interviewing questionnaire included socio-demographic data and clinical data. II) Parental Stress Scale (PSS). III) Quality of Life Scale (QOLS). **Results:** One half of the studied parents had high stress level, less than half had moderate stress level, and one tenth of studied parents had low stress. Furthermore, less than three quarter of the studied parents had poor level of quality of life and less than one tenth of parents had good level of quality of life. **Conclusion:** There was highly statistically significant negative correlation between parental stress and total quality of life among the studied parents; the parents of children diagnostic of leukemia are more prone to face parental stress, which parents who have stress are likely to have impaired quality of life. **Recommendations:** Psycho-educational programs should be integrated as a routine nursing intervention for parents of children with leukemia, to reduce their parental stress and improve quality of life.

**Key words:** - Leukemia, Parental stress, Quality of life, Nursing

### Introduction

Leukemia is cancer of the blood-forming tissues that make up the bone marrow inside large bones. The diseased bone marrow floods the body with abnormal white cells. These cells do not perform the infection-fighting functions of healthy mature white cells. In addition, production of red cells, which carry oxygen, and platelets, which help prevent bleeding, is decreased. Leukemia is the most common type of childhood cancer. It accounted for 30% of all cancers diagnosed in

children younger than 15 years. The two broad classifications of leukemia are acute and chronic; acute lymphoblastic leukemia is the most common type of leukemia found in children (**American cancer society, 2021**).

A diagnosis of childhood leukemia is a devastating experience for any parent and it has been shown to inflict a significant negative impact on their quality of life. This impact may well extend beyond the parent's personal confines to adversely affect the wellbeing of the family. Children with chronic diseases like

leukemia need to be kept under care and supervision for a long time. This causes parents who provide long-term care to experience difficulty, stress, pressure, or burdens, due to the care for the sick person (**Elizabeth, 2020**).

Parental stress can be defined as excess anxiety and tension specifically related to the role of a parent and to parent-child interactions. Parents of child with leukemia are hidden patients in the need of protection from physical and emotional harm. Parents may experience stress regardless of the degree of the child's illness; Parents will be severely stressful after diagnosis of leukemia in their children and this will be more severe when the child is in pain, receives chemotherapy injections, becomes hospitalized. Under chronic exposure of stress, depression and anxiety may exist as a perceived form of psychological status caused by response towards stress (**Uludağ et al., 2020**).

Studies have shown that in highly severe or chronic disease, parents of children tend to have poorer quality of life and higher stress level. Parents of pediatric cancer patients are at risk for experience stress and impaired quality of life (QoL), both during and after treatment, and that major determinants of adverse QoL outcomes are sleep problems and distress. Parents of cancer patients also experienced fatigue, fear, feelings guilty, anxiety, depression, despair, regret, sleep problems, and high social isolation. In addition, parents felt their social relationships were disrupted because they only focused on children so that their own needs were neglected (**Mirzaei et al., 2019**).

Quality of life implies the ability of people to function normally every day and to be satisfied with their participation in everyday

activities. The ability of maintaining these daily activities includes maintaining physical mobility, independence from others, sufficient energy for self-help, social contacts, emotional stability, and absence of pain or other symptoms of discomfort, and adequate sleep and rest. Treatment of children with leukemia can affect daily lives of family caregivers. This can disrupt roles in social life, limit daily activities, disrupt health and physical and emotional balance as well as causing economic problems and creating poor quality of life (**Bektas et al., 2020**).

Nursing role for children with leukemia is more challenging, because the children will have many physical and psychological needs. So that the pediatric oncology nurse not only provide technical care (e.g., Pain management), but also provide care for complex critical ill patients and their parents. The parent's role, their responsibilities, the daily functioning of family and the professional life of parents are negatively impacted and can generate stress and anxiety. Nurses' awareness of psychological problems and quality of life can affect the care of these patients and their parents and improve their psychological well-being (**Bovero et al., 2018**).

### **Significance of the study**

According to **World Health Organization (2021)**, Leukemia is the most common type of childhood cancer. Survival rates have reached over 90% due to the establishment of intense chemotherapy regimens and enhanced supportive care. The global annual incidence of Acute Lymphoblastic Leukemia (ALL) is three per 100,000 children less than 15 year. In the United States, the annual of new cases of ALL was 5,930 and the mortality rate was 1,500 for both sexes. **In Egypt**, childhood leukemia is the most common childhood

## **Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**

malignancy; it represents 33.2 % of all childhood malignancy. The total new cases of leukemia were 4,314 and the total mortality rate was 3,752. (**National Cancer Institute, 2019**).

Parents of children with leukemia are key members of their children's health teams and serve as the primary nurse for them. They may face greater challenges in caring for their children than ordinary parents such as increased therapy expenditures and child care difficulties due to a scarcity of clinical resources and governmental support as well as their socioeconomic status. These issues may have an adverse effect on child care and increase parents stress and affect their quality of life.

### **Aim of the study**

This study aimed to examine the relationship between parental stress and quality of life among parents of children with leukemia.

### **Research Questions**

1. What is the level of parental stress among parents of children with leukemia?
2. Is there a relation between parental stress and quality of life among parents of children with leukemia?

### **Subject and methods**

#### **Research design**

A descriptive design was utilized in this study.

#### **Research setting**

The study was conducted at hematology and oncology clinic at specialized Pediatric hospital in Benha city, Kaluobia Governorate; patient clinic is composed of two clinics for general examination of children and treatment and 57357 hospital for pediatric oncology. The leukemia unit at 57357 hospital includes one

section for both sexes' patients, the capacity of this is 40 beds.

### **Sampling**

A purposive sample consisting of 100 parents (20 from specialized Pediatric hospital in Benha city and 80 from 57357 hospital for pediatric oncology) of children diagnostic with leukemia according to medical team diagnoses who fulfilled the following criteria: - Primary care giver to child at least 6 months, both sexes, agreement to participate in the study, free from psychiatric disorders and free from mental disorders.

### **Tools of data collection**

In order to achieve the aim of the study the following tools were being used:

#### **Tool one:- Structured Interview Questionnaire Sheet:**

Structured interview questionnaire was developed by investigators based on scientific review of literature which consist of three parts:

- **Part I:** Socio-demographic data of parents of children with leukemia which includes parent's age, sex, marital status, educational level, occupation, & residence.
- **Part II:** Socio-demographic data of children with leukemia which includes child age, sex, educational level, child order, & family history of cancer.
- **Part III:** Clinical data for children with leukemia which includes number of years of illness, onset of disease, period of treatment, number of hospitalizations, & current treatment.

#### **Tool two: - Parental Stress Scale (PSs):**

The scale was originally developed by **Berry & Jones (1995)**, was used to measure parental stress for both mothers and fathers. It is a self-report measure that contains 18 items.

Parents were asked to rate each item on a five-point scale: strongly disagree (1) disagree (2), undecided (3), agree (4), strongly agree (5). To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as follows: (strongly disagree = strongly agree) (disagree = agree) (undecided = undecided) (agree = disagree) (strongly agree = strongly disagree). The item scores are then summed. Higher scores on the scale specify a high level of parent stress and low scores indicates low level of parent stress. Overall possible scores on the scale range from 18-90.

### **Scoring system of DASS**

- 18-30 points indicate a low level of parental stress.
- 31-60 points indicate a moderate level of parental stress.
- 61-90 points indicate a high level of parental stress.

### **Tool three: - Quality of Life Scale (QOLS)**

This scale constructed by **World Health Organization Quality of Life Group, (1997)**; to assess the subjective opinion of family caregivers regarding quality of life. It was consisted of a total of 24 questions divided into four domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items). All items are rated on a five-point scale (1= not at all, 2= a little, 3=a moderate amount, 4=very much, 5= an extreme amount). Higher scores indicate better quality of life. The four domains are scaled in a positive direction except for three items, which are reversed before scoring.

### **Scoring system of Quality of Life Scale (QOLS)**

\_ score less than 60 (50%) denote poor quality of life.

\_ 60– 90 (50–75%) indicate moderate quality of life.

\_ More than 90 (75%) denote good quality of life.

### **Content validity of the tools**

The tools were reviewed for appropriateness of items and measuring the concepts through 5 experts in psychiatric & mental health nursing to assure content validity and it were translated into Arabic language then retranslated into English language. Modification was done accordingly; some modification done in parental stress scale; modify some words to be easier and understandable for study sample, for example item 14 was modified from "If I had it to do over again, I might decide not to have child (ren)" to "If I had it to choose again, I might decide not to have child (ren)"

### **Reliability of the tools**

The study tools were tested for its internal consistency by Cronbach's Alpha. Reliability of PS scale is 87, while QOL scale is 85.

### **Ethical considerations**

Approaches to ensure the ethical issues were considered in the study regarding confidentiality and informed consent. Confidentiality was achieved by the use of locked sheets without names of the participants and replaced by numbers. All the participants were informed that the information they provided during the study would be kept confidential and used only for statistical purpose and after finishing the study. Each parent was informed that participation in the study was voluntary, and had the right to withdraw from the study at any time.

### **Pilot study**

A pilot study conducted to test the applicability of the instruments, the feasibility

## **Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**

of the study and estimate the time needed for collecting the data. It was conducted on 10% of the total sample (10 parents) according to the selection criteria. All parents participated in the pilot study included from the study sample.

### **Filed work**

The investigator started data collection by introducing himself to the studied parents and the purpose of the study was simply explained to the parents who agree to participate in the study. Each participant interviewed and assessed individually. Each parent was handed the questionnaire and answered it under observation of the investigator. Parent who can't read well, the investigator helped them to write their answers. The first instrument (Parental Stress Scale) filled in about 10 minutes and the second instrument (Quality of Life Scale) filled in about 15-20 minutes. The process of data collection took about 5 months started in the beginning of May 2021 and ended in the end of September 2021. During the first three months (May, June & July), the investigator collected 20 questionnaires at specialized pediatric hospital at Benha city during the morning shift from 10 am to 12pm, one day per week (Wednesday). (1-2 parents per week; 6-8 parents per month). During the last two months (August & September), the investigator collected 80 questionnaires at 57357 hospital during the morning shift from 10am to 1pm, two days per week (Wednesday & Thursday). (10 parents per week; 40 parents per month).

### **Statistical analysis**

Upon completion of data collection, the collected data were organized, tabulated; statistically analyzed by using an IBM personal computer with Statistical Package of Social Science (SPSS) version 22. Data were presented using descriptive statistics in form of

number and percentage, mean, standard division, and Qualitative variables were comparing using the chi-square test. For quantitative data, person correlation coefficient (r) was used for correlation analysis and degree of significance was identified. A statistically significant difference was considered if p-value was < 0.05. A highly statistically significant difference was considered if p-value was < 0.001.

### **Results**

Table (1) shows that less than half (46%) of the children's age is <5 years with Mean  $\pm$  SD ( $8 \pm 5.24$ ), more than two thirds (68%) of them are male, less than half (46%) of children are at preschool age, less than half (44%) of them are the first between siblings and most (88%) of them haven't family history of cancer.

Table (2) shows that two third (66%) of the children have <1 year regarding number of years of illness, more than half (54%) of children is <5 years regarding their onset of disease, less than three quarters (70%) of them are <1year regarding period of treatment, less than two third (64%) of them had hospitalized 1-3 times and more than half (52%) of their current treatment is chemotherapy.

Table (3) shows that less than one third (32%) of the studied parents has 40 years and more regarding their age with Mean  $\pm$  SD ( $35 \pm 9.77$ ), more than half (60%) of them is female, majority (80%) of parents are married, more than one third (38%) of them has intermediate education, less than two thirds (64%) of parents are not working, and less than three quarters (70%) of them live in rural area.

Figure (1) shows that one half (50%) of the studied parents had high stress and less than half (40%) of studied parents had moderate

stress, and one tenth (10%) of studied parents had low stress.

Figure (2) shows that less than three quarter (70%) of the studied parents had poor level of quality of life and less than one tenth (8%) of parents had good level of quality of life.

Table (4) illustrates that, there is a highly statistically significant relation between total stress level among the studied parents and their marital status. Also, there is a statistically significant relation between parents' stress level and their age, sex and educational level, while there is no statistically significant relation between total stress level among the studied parents and their residence and occupation.

Table (5) illustrates that, there is a highly statistically significant relation between total level of quality of life among the studied parents and their age, and sex. Also, there is a statistically significant relation between total level of quality of life and their marital status, and occupation, while there is no statistically significant relation between total level of quality of life and their educational level and residence.

Table (6) show that, there is highly statistically significant negative correlation between total parental stress and total quality of life among the studied parents at P-value  $= < 0.001$ .

**Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**

**Table (1) Percentage distribution of socio-demographic characteristics of the children (n=100).**

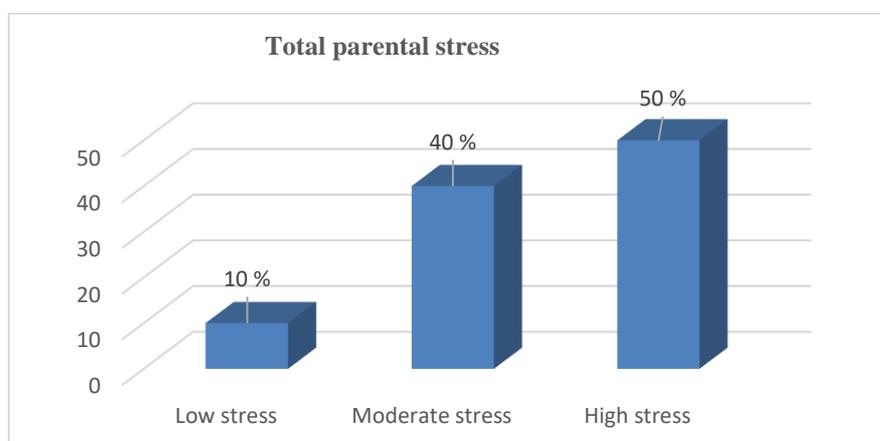
<b>Socio-demographic characteristics</b>	<b>No.</b>	<b>%</b>
<b>Age (years)</b>		
- <5 year	46	46
- 5 -<10 year	18	18
- 10 -<15 year	22	22
- 15-18 year	14	14
<b>Mean ± SD</b>	<b>8 ± 5.24</b>	
<b>Sex</b>		
- Male	68	68
- Female	32	32
<b>Educational level</b>		
- Preschool age	46	46
- Primary	22	22
- Preparatory	14	14
- Secondary	18	18
<b>Birth order of child</b>		
- The first	44	44
- Middle	22	22
- The last	34	34
<b>Family history of cancer?</b>		
- Yes	12	12
- No	88	88

**Table (2) Percentage distribution of clinical characteristics of the children (n=100).**

<b>Clinical characteristics</b>	<b>No.</b>	<b>%</b>
<b>The numbers of years of illness?</b>		
- <1 year	66	66
- 1 -<5 year	30	30
- 5 year or more	4	4
<b>Onset of disease</b>		
- <5 year	54	54
- 5-<10 year	18	18
- 10-<15 year	14	14
- 15-18 year	14	14
<b>The period of treatment for the disease</b>		
- <1 year	70	70
- 1-<2 year	26	26
- 2 year or more	4	4
<b>Number of hospitalizations</b>		
- 1-3 times	64	64
- 4-6 times	30	30
- 7 times or more	6	6
<b>Current treatment</b>		
- Follow up or drugs	8	8
- Radiotherapy	4	4
- Chemotherapy	52	52

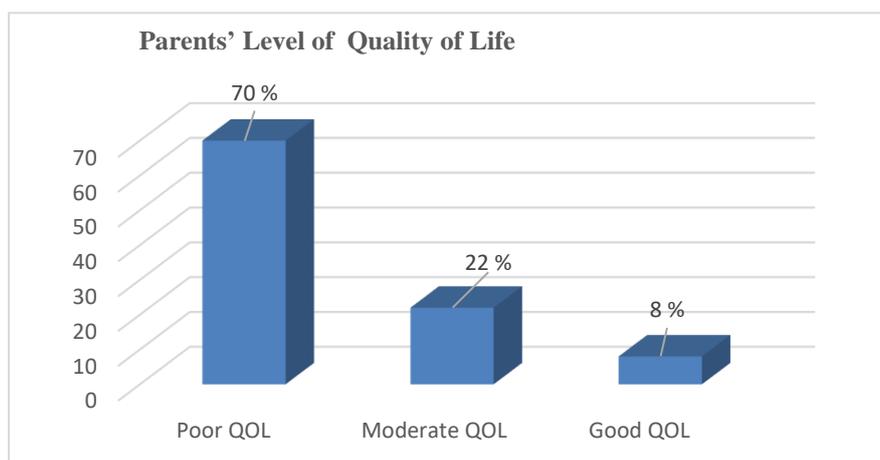
**Table (3) Percentage distribution of socio-demographic characteristics of the parents (n=100).**

Socio-demographic characteristics	No.	%
<b>Age (years)</b>		
- <25 year	10	10
- 25 -<30 year	30	30
- 30 -<35 year	12	12
- 35-<40 year	16	16
- 40 year and more	32	32
<b>Mean ± SD</b>	<b>35 ± 9.77</b>	
<b>Sex</b>		
- Male	40	40
- Female	60	60
<b>Marital status</b>		
- Married	80	80
- Widowed	10	10
- Divorced	10	10
<b>Educational level</b>		
- Illiterate	32	32
- Basic education	22	22
- Intermediate education	38	38
- University education	8	8
<b>Occupation</b>		
- Employee	8	8
- Free business	28	28
- Not working	64	64
<b>Residence</b>		
- Rural	70	70
- Urban	30	30



**Figure (1) Percentage distribution of total level of stress among the studied parents (n=100).**

**Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**



**Figure (2) percentage distribution of total level of quality of life among the studied parents (n=100).**

**Table (4) The relationship between parents' socio-demographic characteristics and total stress level (n=100)**

<b>Socio-demographic characteristics</b>	<b>No</b>	<b>Mild stress</b>	<b>Moderate stress</b>	<b>High stress</b>	<b>X<sup>2</sup></b>	<b>P-Value</b>
<b>Age (years)</b>						
-<25 year	10	2	2	6		
-25 -<30 year	30	2	18	10		
-30 -<35 year	12	2	4	6		
-35 -<40 year	16	4	4	8		
-40 year or more	32	0	12	20	16.6	.034*
<b>Sex</b>						
-Male	40	2	22	16		
-Female	60	8	18	34	6.7	.034*
<b>Marital status</b>						
-Married	80	8	40	32		
-Widowed	10	0	0	10		
-Divorced	10	2	0	8	20.4	.000**
<b>Educational level</b>						
-Illiterate	32	6	16	10		
-Basic education	22	2	6	14		
- Intermediate education	38	0	14	24		
-University education	8	2	4	2	15.4	.017*
<b>Occupation</b>						
-Employee	8	0	4	4		
-Free business	28	2	12	14		
-Not working	64	8	24	32	5.61	.230
<b>Residence</b>						
-Rural	70	6	30	34		
-Urban	30	4	10	16	1.05	.592

**Table (5) The relationship between parents' socio-demographic characteristics and total quality of life (n=100)**

<b>Socio-demographic characteristics</b>	<b>No</b>	<b>Poor QOL</b>	<b>Fair QOL</b>	<b>Good QOL</b>	<b>X<sup>2</sup></b>	<b>P-Value</b>
<b>Age (years)</b>						
-<25 year	10	8	0	2		
-25 -<30 year	30	8	20	2		
-30 -<35 year	12	10	2	0		
-35 -<40 year	16	8	4	4		
-40 year or more	32	16	16	0	30.8	.000**
<b>Sex</b>						
-Male	40	12	24	4		
-Female	60	38	18	4	10.8	.004**
<b>Marital status</b>						
-Married	80	34	38	8		
-Widowed	10	6	4	0		
-Divorced	10	10	0	0	12.9	.012*
<b>Educational level</b>						
-Illiterate	32	14	14	4		
-Basic education	22	14	6	2		
-intermediate education	38	20	18	0		
-University education	8	2	4	2	10.4	.107
<b>Occupation</b>						
-Employee	8	2	6	0		
-Free business	28	10	14	4		
-Not working	64	38	22	4	12.7	.013*
<b>Residence</b>						
-Rural	70	34	32	4		
-Urban	30	16	10	4	2.4	.303

**Table (6) Correlation between total parental stress and total quality of life among the studied parents (n=100).**

<b>Total parental stress</b>	<b>Quality of life scale</b>	
	<b>R</b>	<b>P</b>
	-.653	.000**

**Discussion**

Childhood cancer has a profound impact on the parents of diagnosed children; Parents are at risk of experiencing a variety of

psychological problems such as depression, anxiety, and acute stress disorder. Time since diagnosis of acute leukemia in a child showed symptoms of stress in parents which

## **Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**

constitutes a major challenge hampering their quality of life. **Fertelli & Tuncay, (2019)**. So, the current study aimed to assess the relationship between parental stress and quality of life among parents of children with leukemia.

According to socio-demographic characteristics of the children with leukemia, the current study result showed that less than half of the studied children's age was less than 5 years with Mean  $\pm$  SD ( $8 \pm 5.24$ ), Regarding child sex, more than two thirds of them were boys, this result may be due to leukemia is more prevalence in boys in young age less than 15 years old. This result was in agreement with **Al-Buraiki et al., (2021)** who conducted study on (Association of parental, child, and environmental factors with the occurrence of childhood leukemia in Upper Egypt) and showed that more than two thirds of them were boys and the most affected age group was children 5 years or younger.

Regarding child level of education, less than half of children were at preschool age, and were the younger child between their siblings and most of them hadn't family history of cancer. This result was consistent with **Talaat, (2017)** who conducted study on (Psychological Problems and Coping Patterns among Parents of Children with Leukemia) and reported that more than one third of the children were the younger and the majority of them hadn't family history of cancer. Conversely, this result was inconsistent with **Wang et al., (2018)** who conducted study on (Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China) and reported that more than half of the children were at preschool age.

Concerning clinical characteristics of the studied children, the current study showed that two third of the children had less than 1 year

regarding number of years of illness and more than half of children were less than 5 years regarding their onset of disease; this result was in disagree with **Vercasson et al., (2020)** who conducted study on (Quality of life in parents of childhood leukemia survivors) and reported that only one tenth of the studied children had less than 1 year regarding number of years of illness. As well, the current study showed that, less than three quarters of them were less than 1 year regarding period of treatment, less than two third of them had hospitalized 1-3 times and more than half of their current treatment was chemotherapy. This result was similar to the study of (Factors Affecting Quality of Life in Patients with Pediatric Leukemia during Induction Chemotherapy) done by **El Desouky et al., (2018)** who reported that less than two third of the children had hospitalized 1-3 times and more than half of their treatment was chemical.

Regarding to socio-demographic characteristics of the studied parents, the current study result showed that, less than one third of the studied parents had 40 years or more regarding their age with Mean  $\pm$  SD ( $35 \pm 9.77$ ). Regarding their sex, more than half of them were female, this result may be due to mothers are considered the primary caregiver for their children and more responsible for caring than father related to Egyptian community. Regarding marital status, majority of parents were married, this result may be due to the nature of this study that assessed the variables for parents. This finding was similar to the study of (Coping Strategies among Parents of Children with Acute Lymphoblastic Leukemia) done by **Sutan et al., (2018)** who reported that mean of parents' age was 35, more than half were mothers, and the majority of parents were married. On the other hand, this result is in disagreement with **Wang et al., (2018)** who reported that more than half of the

parents were 40 years old or more and more than half of them were male.

Also, the result of the current study revealed that more than one third of the studied parents had intermediate level of education. Less than two thirds of parents were not working, this result may be due to higher percentage of studied parents were mothers who were housewife lived in rural area. Less than three quarters of them lived in rural areas, this result may be due the life with their families and provide emotional support from life in rural area and Benha children hospital serves a large sector of villages around it. This finding was similar to the study done by **Al-Buraiki et al., (2021)** who reported that more than one third of the studied parents had intermediate education, less than two third of them were not working and the majority of them lived in rural area. On the other hand, this result is in disagreement with **Talaat, (2017)** who reported that half of the studied parents were had job and the majority of them were lived in urban area.

Concerning to total level of stress among the studied parents, the current study showed that one half of the studied parents had high stress level and less than half of them had moderate stress, while one tenth of them had low stress. From the investigator point of view, this result may be due leukemia diagnoses is a life threatening and its invasive treatment and side effect of treatment cause physical and psychological stress among parents of those children. This result was in agreement with, **Sherief et al., (2018)** who conducted study on (Psychological impact of chemotherapy for childhood acute lymphoblastic leukemia on patients and their parents) and stated that, one half of parents had severe stress. Conversely, this result disagree with **Irwanto et al., (2020)** who revealed that less than one fifth of parents who caring for their children with leukemia

had severe stress and more than half of them had moderate stress.

According to total level of quality of life among the studied parents, the result of current study illustrated that less than three quarter of the studied parents had poor level of quality of life and less than one tenth of parents had good level of quality of life. From the investigator point of view, this result may be due to after child diagnosis with cancer, parents experience a feeling of physical, social and psychological problems. The problems include insomnia, fatigue, isolation, fear, stress, anxiety and depression, which may negatively affect the quality of life (QOL) of those parents. This result is supported with **Vercasson et al., (2020)** who reported that less than three quarter of parents had poor level of quality of life. Conversely, this result is disagreement with the study of **Yu et al., (2018)** conducted on (Factors associated with the quality of life of family caregivers for leukemia patients), showed good QOL of more than half of family caregivers for leukemia patients.

Concerning to the relationship between parents' socio demographic characteristics and total stress level, the current study illustrated that, there was a highly statistically significant relation between total stress level among the studied parents and their marital status. From the investigator point of view, this result may be due to widowed or divorced parents had more responsibility; couple supports each other to tolerate responsibility of child care and treatment than divorced or widowed. This result is accordance with **Bemis et al., (2018)** who conducted study on (Childhood cancer in context: Socio-demographic factors, stress, and psychological distress among mothers and children) and reported that there was a highly statistically significant relation between total stress level among the studied parents and their marital status. Conversely, this result is in

## **Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia**

disagreement with **Zarina et al., (2017)** who conducted study on (Parenting Stress in Childhood Leukaemia) and found that there was no statistically significant relation between total stress level and their marital status.

As well, the result of current study showed that, there was a statistically significant relation between parents' stress level and their age, sex and educational level. From the investigator point of view, this result may be due to mothers assume the large part of child's care duties and home care than fathers, and younger parents may experience greater burden. This result is in agreement with **McCarthy et al., (2018)** who conducted study on (Predictors of acute and posttraumatic stress symptoms in parents following their child's cancer diagnosis) and reported presence of statistically significant relation between parents' stress level and their age and sex. Conversely, this result disagreement with **Zarina et al., (2017)** who found that there was no statistically significant relation between total stress level among the studied parents and their age, sex and educational level.

The result revealed, there was no statistically significant relation between total stress level among the studied parents and their residence and job. From the investigator point of view, this result may be due to care and treatments of childhood leukemia are expensive and can cause financial burden for all parents. This result is accordance with **Sultan et al., (2018)** who conducted study on (A systematic review on factors and consequences of parental distress as related to childhood cancer) and reported that there was no significant relation between stress level among the studied parents and their residence and job.

Concerning to the relationship between parents' socio demographic characteristics and

total quality of life, the current study illustrated that, there was a highly statistically significant relation between total quality of life among the studied parents and their age and sex. From the investigator point of view, this result may be due to parents don't have awareness about leukemia and its consequences which locate burden on their daily livings activates which consequently affect their quality of life, also, woman have the main role as administration of children, households, and husbands. This result is accordance with **Mondal et al., (2020)** who conducted study on (A Study to Assess the Quality of Life (QOL) Among Parents of Children with Acute Lymphoblastic Leukemia (ALL) Attending Oncology Out Patient Department (OPD) In Selected Hospital of Kolkata) and reported that there was a highly statistically significant relation between total quality of life among the studied parents and their age and sex. Conversely, this result is in disagreement with **Rohmah et al., (2018)** who found that there was no statistically significant relation between total quality of life among the studied parents and their age and sex.

As well, the result of current study showed that, there was a statistically significant relation between parents' total quality of life and their marital status and occupation. From the investigator point of view, this result may be due to the fact that marriage change the life of each couple and affecting their quality of life, and the cancer treatment can cause financial burden which require more financial resources. This result is in agreement with **Ganjiwale et al., (2018)** who conducted study on (Quality of life and coping strategies of caregivers of children with physical and mental disabilities) and reported presence of statistically significant relation between parents' QOL level and their marital status and job. Conversely, this result disagreement with **El Desouky et al., (2018)**

who found that there was no statistically significant relation between total QOL level among the studied parents and their marital status and job.

The result revealed, there was no statistically significant relation between total quality of life among the studied parents and their educational level and residence. From the investigator point of view, this result may be due to the culture taken about cancer that is a fatal disease with no cure until death. This result is accordance with **Choi et al., (2018)** who conducted study on (Factors associated with quality of life among family caregivers of terminally ill cancer patients) and reported that there was no significant relation between QOL among the studied parents and their educational level and residence.

According to correlation between total quality of life and total parental stress among the studied parents, the current study showed that there was highly statistically significant negative correlation between parental stress and total quality of life among the studied parents. From the investigator point of view, this result may be due to anxiety, stress and depressive symptoms, which occurred in substantial percentage of parents during childhood cancer. Psychiatric problems had an adverse impact on parents' quality of life. This result agreement with, **Yildirim et al., (2021)** who conducted study on (The relationship between the care burden and quality of life of parents who have children with hematological diseases) & **Haya et al., (2019)** who conducted study on (Family caregivers' perspectives for the effect of social support on their care burden and quality of life) they reported that that there was highly statistically significant negative correlation between parental stress and total quality of life among the studied parents.

## **Conclusion**

**From the result of the present study, one can conclude that:**

The study concluded that the parents of children diagnostic of leukemia are more prone to face parental stress, which parents who have stress are likely to have impaired quality of life. One half of the studied parents had high stress level, less than half had moderate stress level, and only one tenth of studied parents had low stress. Furthermore, less than three quarter of the studied parents had poor level of quality of life and less than one tenth of parents had good level of quality of life. Also, there was highly statistically significant negative correlation between parental stress and total quality of life among the studied parents.

## **Recommendations**

- Psycho-educational programs should be integrated as a routine nursing intervention for parents of children with leukemia, to reduce their parental stress and improve quality of life.
- Conducting of counseling sessions for parents of children with leukemia, to enhance their wellbeing, reduce stress, and consequently, improve their quality of life.
- Increasing parents' awareness about leukemia and coping strategies with its consequences.
- Conducting spiritual and religious supporting group sessions to reduce psychological problems. This could provide parents of children with leukemia a power to overcome difficulties, and a more optimistic view of the future.
- Liaison psychiatric nurse must be available to deal with psychiatric problems of those parents and their children.
- Palliative care should be an integral part of cancer treatment.
- Further researches are necessary to assess and enhance psychological conditions of

## Relationship between Parental Stress and Quality of Life among Parents of Children with Leukemia

the children with leukemia recreational progress and palliative care.

- Further studies by using larger probability sample for generalization of the results.

### References

**Al-Buraiki, T., Hany, A., Riad, K., & Osman, D. (2021).** Association of parental, child, and environmental factors with the occurrence of childhood leukemia in Upper Egypt; 51(1):10-18.

**American Cancer Society (2021).** Detention of leukemia: American Cancer Society. Cancer.org.

<https://www.cancer.org/involved/fundraise/relay-for-life.html>. Accessed on 4/7/2021.

**Bektas, İ., Kır, M., Yıldız, K., Genç, Z., Bektas, M., & Ünal, N. (2020).** Symptom frequency in children with congenital heart disease and parental care burden in predicting the quality of life of parents in Turkey. *Journal of Pediatric Nursing*, 53, e211–e216.

**Bemis, H., Yarboi, J., Gerhardt, C., Vannatta, K., Desjardins, L., Murphy, K., & Compas, B. (2018).** Childhood cancer in context: Socio-demographic factors, stress, and psychological distress among mothers and children. *Journal of pediatric psychology*, 40(8), 733-743.

**Berry, J., & Jones, W. (1995).** The Parental Stress Scale: initial psychometric evidence. *Journal of Social and Personal Relationships*, 12, 463 – 472.

**Bovero, M., Giacomo, C., Ansari, M., & Roulin, M. (2018).** Role of advanced nurse practitioners in the care pathway for children diagnosed with leukemia. *European Journal of Oncology Nursing*, 36, 68-74.

**Choi, Y., Hwang, S., Hwang, I., Lee, Y., Kim, S., Kim, M., & Youn., H. (2018).** Factors associated with quality of life among family caregivers of terminally ill cancer patients. *Psych oncology*; 25:217–24.

**El Desouky, E., Noaman, M., Shalaby, L., & Shaaban, S. (2018):** e, *The Egyptian Journal of Community Medicine*: 35 (4), p.15-30.

**Elizabeth, G. (2020).** *Physiological Stress Reactivity in Childhood Leukemia and Lymphoma Patients and an Exploration of Neurological and Behavioral Characteristics Associated with Stress Regulation*; Ph.D. University of Toronto, Canada, P.75.

**Fertelli, T., & Tuncay, F. (2019).** Relationship between care burden, social support and quality of life in caregivers of individual with stroke. *Journal of Academic Research in Nursing*, 5(2), 107–115. <https://doi.org/10.5222/jaren.2019.52386>.

**Ganjiwale, D., Ganjiwale, J., Sharma, B., Mishra, B. (2018).** Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of family medicine and primary care*; 5(2):343.

**Haya, M., Ichikawa, S., Wakabayashi, H., & Takemura, Y. (2019).** Family caregivers' perspectives for the effect of social support on their care burden and quality of life: A mixed-method study in rural and sub-urban central Japan. *Tohoku Journal of Experimental Medicine*, 247, 197–207.

**Irwanto, R., Prihaningtyas, A., & Mustakim, D. (2020).** Impact of Caregiver's Psychological Aspects towards Quality of Life of Children with Acute Lymphoblastic Leukemia (ALL). *Asian Pacific Journal of Cancer Prevention: APJCP*, 21(9), 2683.

**McCarthy, C., Ashley, M., Lee, J. & Anderson, A. (2018).** Predictors of acute and posttraumatic stress symptoms in parents following their child's cancer diagnosis. *Journal of Traumatic Stress* 25, 558–566.

**Mirzaei, M., Yasini, A, Ardekani, M., & Dehghani, A. (2019).** Prevalence of depression, anxiety and stress among adult population: Results of Yazd Health Study. *Iran*

J Psychiatry. 2019; 14:137–46. [PMC free article] [PubMed] [Google Scholar]

**Mondal, M., Dey, T., & Poddar, S. (2020).** A Study to Assess the Quality of Life (QOL) Among Parents of Children with Acute Lymphoblastic Leukemia (ALL) Attending Oncology Out Patient Department (OPD) In Selected Hospital of Kolkata, West Bengal, India, Malaysian Journal of Medicine and Health Sciences; 16(SUPP10): 125-130, Nov 2020

**National Cancer Institute. (2019).** Statistics of pediatric cancers/ United States National Institutes of Health. <https://www.cancer.gov/types/childhood-cancers/child-adolescentcancers-fact-sheet> Accessed on.12/3/2019.

**Rohmah, B., Anis N., & Bariyah, K. (2018).** Kualitas hidup lanjut usia [Quality of life of elderly]. Jurnal Keperawatan, 3(2), 120–132.

**Sherief, M., Kamal, M., Abdalrahman, M., Youssef, M., Abd Alhady, A., Ali, S., & Hashim, M. (2018).** Psychological impact of chemotherapy for childhood acute lymphoblastic leukemia on patients and their parents. Medicine, 94(51).

**Sultan, S., Leclair, T., Rondeau, E., Burns, W., & Abate, C. (2018).** A systematic review on factors and consequences of parental distress as related to childhood cancer, European Journal of Cancer Care 25, 616–637.

**Sutan, R., Al-Saidi, A., Latiff, A., & Ibrahim, M. (2018).** Coping Strategies among Parents of Children with Acute Lymphoblastic Leukemia .Health, 9, 987-999.

**Talaat, f., (2017).** Psychological Problems And Coping Patterns Among Parents Of Children With Leukemia; M.D. Helwan University. Helwan, Egypt, P75-85.

**Uludağ, A., Tüfekç, F., & Ceviz, N. (2020).** The connection between social support and

caregiver burden and life satisfaction of the parents whose children have congenital heart disease. YOBU Faculty of Health Sciences Journal, 1(1), 11–20.

**Vercasson, C., Ansoborlo, S., Gandemer, V., Paillard, c., Sirvent, N., & Berbis, L. (2020).** Quality of life in parents of childhood leukemia survivors. A French Childhood Cancer Survivor Study for Leukemia study, Pediatric Blood Cancer. 2020; 67: e28419.

**Wang, G., Shen, N., Zhang, X., & Shen, M. (2018).** Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China, Support Care Cancer (25); p.3703–3713.

**World Health Organization (2021).** cure all framework : who global initiative for childhood cancer. Increasing access advancing quality. Searching lives.who.

**World Health Organization Quality Of Life (WHOQOL) Group (1997):** Development of the World Health Organization WHOQOL-Brief quality of life assessment. Psycho Med 28:551–558.

**Yildirim, H., Yayan, Y., & Suna, D. (2021).** The relationship between the care burden and quality of life of parents who have children with hematological diseases, Journal of Pediatric Nursing,

**Yu, H., Li, M., Liu, C., & Ma, Y. (2018).** Factors associated with the quality of life of family caregivers for leukemia patients in China, Health and Quality of Life Outcomes, 15(15), P2.

**Zarina, A., Radhiyah, R., Hamidah A., & Rahman, J. (2017).** Parenting Stress in Childhood Leukaemia, Med & Health; 7(2): 73-83

## العلاقة بين الإجهاد الأبوي وجودة الحياة لدى آباء الأطفال المصابين بمرض سرطان الدم عبدالمسيح نصري يعقوب سناده - نجلاء فتحي محمد العطار - ضحى عبدالبصير محمود

ان تشخيص إصابة الأطفال بمرض سرطان الدم هي تجربة مريرة لكلا الوالدين ، والتي بدورها تؤدي الي مستوى من الجهاد الأبوي والذي بدوره يؤثر سلبيا علي جودة الحياة للآباء. تم إستخدام التصميم الوصفي في هذه الدراسة. أجريت هذه الدراسة الدراسة في عيادة أمراض وأورام الدم في مستشفى الأطفال التخصصي في مدينة بنها في محافظة القليوبية ، ومستشفى 57357 لعلاج أورام الأطفال بمصر. شملت عينة الدراسة 100 من الآباء للأطفال الذين تم تشخيص إصابتهم بسرطان الدم خلال فترة جمع البيانات (20من مستشفى الأطفال التخصصي و 80 من مستشفى 57357 لعلاج أورام الأطفال). حيث أظهرت النتائج فيما يتعلق بمستوى الإجهاد الأبوي أن 50% من الآباء الذين خضعوا للدراسة يعانون من مستوي إجهاد شديد ، و 40% منهم يعانون من مستوي إجهاد متوسط ، و 10% منهم يعانون من مستوي إجهاد منخفض ,وأوضحت نتائج الدراسة أن هناك علاقة سلبية ذات دلالة إحصائية عالية بين مستوي الأجهاد الأبوي الكلي وجودة الحياة الكلية بين الآباء الخاضعين للدراسة. كما اوصت الدراسة بأنه يجب دمج برامج تثقيفية نفسية كتدخل تمريضي معتاد لآباء الأطفال المصابين بمرض سرطان الدم للعمل علي تقليل الضغوط النفسية لديهم الذي تباعا يحسن وجودة الحياة لديهم.