

Resilience and Psychological Wellbeing among Parents of Leukemic Child at 57357 Hospital

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Abstract

Background: Parents of child with leukemia are hidden patients in need of protection, which they have a significant negative impact on their psychological wellbeing. Resilience is an aspect of psychosocial care that affects the parents' well-being. **Aim:** This study aimed to assess resilience and psychological wellbeing among parents of child with leukemia. **Design:** A descriptive research design was utilized in this study. **Setting:** this study was carried out in children's cancer hospital in Egypt 57357 at fifth floor. **Subjects:** simple random sample of 93 parents of child with leukemia. **Tools:** 1) Interviewing Socio-Demographic Questionnaire, 2) Connor-Davidson Resilience scale, 3) Ryff's Psychological Well-Being Scale. **Results:** the study revealed that half of parents of child with leukemia had moderate levels of resilience and psychological wellbeing. **Conclusion:** The current study results revealed that there was positive significant correlation between resilience and psychological well-being among parents of child with leukemia. Ultimately, these results may assist the research in Psychiatric Health Nursing department to design interventions that influencing resilience among parents of child with leukemia. **Recommendations:** Future research to assess the factors that influencing resilience among parents of child with cancer.

Key words: resilience, psychological wellbeing, leukemia, parents caregivers.

Introduction

Parents of child with leukemia are hidden patients in need of protection from physical and emotional harm, because of childhood leukemia affects not only the child, but also extends to their parents. Having a child with leukemia can induce feelings of stress, increases the burdens and places the entire family at risk, and that is have negative impacts on the psychological well-being of the parents (Bernard, et al., 2017).

Resilience is a personality trait that allows parents to withstand stress and adapt to the new circumstance. Also, resilience is an important attribute which provides parents with the capacity to resist destructive behaviors such as social withdrawal, depression, indifference and other negative

behaviors that might emerge during child's illness (Hellman, Worley & Munoz, 2018).

Psychological well-being is the functioning with optimal effectiveness in parents' life, which comprise of good mental health, life satisfaction, positive emotions, self-acceptance and purpose in life. Psychological well-being is the ability to communicate coordinately with others to improve social and personal environment. So, Psychological well-being helps in improving anxiety, depression and stress among the parents of child with leukemia (Balfe, et al., 2018).

Resilience is important for enhancing the psychological well-being among parents of child with leukemia and potentially lessening the severity of the existing

burdens. Resilience linked to close association with psychological well-being, which they are vital to developing efficient problem solving skills, building and maintaining interpersonal relationships and realistic goal setting, all of which greatly enhance the parents' abilities to perform and contribute meaningfully in their daily life while providing the care for their child (Eilertsen, et al., 2016).

Significance of the study

Caring a child with leukemia inflicts negative impact on the psychological well-being among the parents which result from the combination of pressure, tension, anxiety, depression and diminished quality of their lives (Chivukula, Kota & Nandinee, 2018).

Resilience among parents of child with leukemia brings a positive change in recovery and adaptation. Resilience sustains parents' health, well-being and capacity to care; it expands capability and reduces vulnerability to stress. Hence, resilience is a major and integral part of psychological health care of those parents (Kaboudi, et al., 2018).

Psychological well-being encourages parents for better adaptation and positive psycho-social outcomes during the treatment of their child, which improving their inner strength and enhancing positive psychological functioning (Hendrix, et al., 2016).

Resilience and psychological well-being are important in establishing a holistic approach to address both physical and psychological status. Resilience is directly related to the psychological well-being, which results in having the ability to cope with the new situations (Halstead, et al., 2018). So, the present study aims to assess resilience and psychological well-being among parents of child with leukemia.

Aim of the study

This study aimed to assess resilience and psychological well-being among parents of leukemic child at 57357 hospital.

Research questions

1. What are the levels of resilience among parents of child with leukemia?
2. To what extent having child with leukemia affecting the psychological wellbeing of parents?

Subjects and Methods

The methodology of the current study will be portrayed according to the following four designs:

- Technical design.
- Operational design.
- Administrative design.
- Statistical design.

I- Technical Design: The technical design includes study design, study setting, subjects and methods and tools that used in data collection.

Research design:

A descriptive research design was conducted to fulfill the aim of the study and answer the research questions. It helps the researcher to describe and document aspects of a situation as it naturally occurs. As well, this design helps to establish a database for future research.

Setting:

The study was conducted in children's cancer hospital in Egypt 57357 at fifth floor.

Subject:

A simple random sample of 93 parents caring child with leukemia in the previously mentioned settings according to following criteria: caring for leukemic child at 57357 hospital. Type of sample

calculation of selection: $S = \frac{X^2NP}{(N-1) + X^2P} (1-p) \div d^2$

Tools of data collection:

Data were collected using the following tools:

1- Interviewing Socio-demographic questionnaire:

It was designed by the researcher, based on reviewing related literatures, then; it was revised by using of panel of experts for the content validity, written in Arabic language to assess all the related socio-demographic characteristics of parents caring for child with leukemia and socio-demographic characteristics of child with leukemia and it was divided into two parts:-

a- First part (Socio Demographic data of parents): This part includes socio demographic characteristics of parents of child with leukemia such as: sex, age, place of residence, educational level, income per month, and number of hours of care provided to the child, activities that increase the ability of parents to care for their child.

b- Second part (Socio demographic data of the child): This part includes socio demographic characteristics of child with leukemia such as: age at detection of the disease.

2- Connor-Davidson Resilience scale:

The scale was originally developed by Connor-Davidson (2003) and adapted by the researcher to assess resilience among parents of child with leukemia. The scale consisted of 25 items classified into 5 sections: Personnel competence, Tolerance of negative effects and strengthening against stress, Positive acceptance of change, Self-control, Spiritual influence.

❖ Scoring system:

Each item was rated on a five point on Likert scale ranged from 1-5. The answers of each question converted to numerical data.

3- Ryff's Psychological Well-Being Scale:

The scale was originally developed by Ryff (1989) and adapted by the researcher to assess psychological wellbeing among parents of child with leukemia. The scale consisted of 42 items which classified into six subscales including: Autonomy, Environmental mastery, Personal growth, Positive relations with others, Purpose in life, Self-acceptance. Each subscale consisted of seven items.

❖ Scoring system:

Each item was rated on six point Likert scale ranged from (1-6). The answer of each question converted to numerical data.

II. Operational Design: The operational design includes the preparatory phase, pilot study and field work.

Preparatory phase:

It included reviewing current, past, local and international related literature and theoretical knowledge of differ aspects of the study using books, articles, internet, periodical and magazines to develop tools for data collection.

Validity of tools:

To achieve the criteria of trustworthiness of the tools of the data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability by jury group consisting of six experts in psychiatric nursing department at faculty of nursing of Ain Shams University. The required corrections and modification were done and the researcher revised each tool and modified some statements under supervision of the researcher supervisor.

Reliability of tools:

It was measured using Cronbach's. Alpha coefficient, it was (0.930) for factors contributing to resilience and (0.961) for psychological wellbeing.

Pilot study:

The pilot study was carried out for 10 % of the sample (10 parents of leukemic child) to test the reliability, clarity of questions and applicability of the tools, and the time needed to complete them then the tools were modified according to the findings of the pilot study. Subjects who shared in the pilot study were excluded from the main study sample.

Field work:

The field work started from February 2018 to August 2018. The researcher met parents and explained the aim and the nature of the study and the method of filling questionnaire. Data was collected three days per week from fifth floor at children's cancer hospital. The time needed to filling questionnaire sheet ranged from (30:40) minutes. The average number of completed questionnaire daily was two questionnaires.

Ethical considerations:

Before conducting the study, the respondent rights was protected by ensuring voluntary participation, so the informed consent was obtained from each participant after explaining the aim of the study, its potential benefits, methods for filling data collection tools and expected outcomes. The respondent rights to withdraw from the study at any time were assured. Confidentiality of data obtained was protected by allocation code number to the questionnaire sheet. Subjects were informed that the content of the tool used for the research purpose only.

III. Administrative Design

An official letter of approval was taken from the dean of the faculty of nursing at Ain Shams University, a letter containing

the title and the aim of the study. It was directed to the director of children's cancer hospital to obtain his approval of data collection.

IV. Statistical Design

The statistical analysis of data was done by using the statistical package for social science (SPSS) program, version 22. The first part of data was descriptive data which was revised, closed, tabulated and statistically analyzed using percentage, arithmetic mean(x) and standard deviation (SD). The following tests were used to test relations for significance, for quantitative data by chi-square tests correlation by Pearson correlation. Degree of significance results were:

- P. Value > 0.5 (Not significant).
- P. Value ≤ 0.05 (Significant).
- P. Value ≤ 0.001 (Highly significant).

Results

Figure (1): in relation to characteristics of studied sample, this figure represents that, more than two thirds (69.9%) of parents caregivers were mothers and one third (30.1%) of parents caregivers were fathers from the total study.

Figure (2): clarifies more than one quarter (29%) of parents was from 25 to less than 30 years and less than one quarter (10.8%) was above 40 years from the total study.

Figure (3): represent that about two thirds (67.7%) of parents hadn't enough monthly income and about one third (32.3%) had enough monthly income from the total study.

Figure (4): show that about two thirds (68.8%) of parents provide care to the child more than eight hours per day. Meanwhile, less than tenth (5.4%) of parents provide care less than one hour per day from the total study.

Table (1): illustrate that 61.3% of the child with leukemia in the study were females, 39.8% of the children in the study

their age less than five years. As regard to age of detection with leukemia 46.2% of children were detected at age < 5 years, 40.9% of children were the youngest children between their siblings.

Figure (5): clarifies that parents had low level of personal competence, positive acceptance of change & self-control. They represent 50.5%, 47.3% & 48.4% respectively. Meanwhile, they had high level (47.3%) concerning spiritual influence. Finally, 57.0% of parents had moderate level

regard tolerance of negative effects and strengthening against stress.

Table (2): displays that; 50.5% of parents had moderate levels of resilience.

Table (3): represents that 50.5% of parents had moderate level of psychological well-being.

Table (4) show that, level of resilience among parents of child with leukemia is positively highly related with their level of psychological well-being.

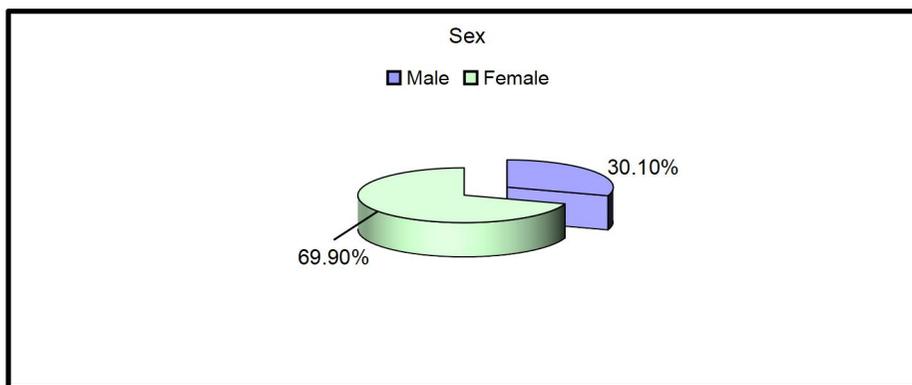


Fig (1): Percentage distribution of parents of leukemic child according to their sex.

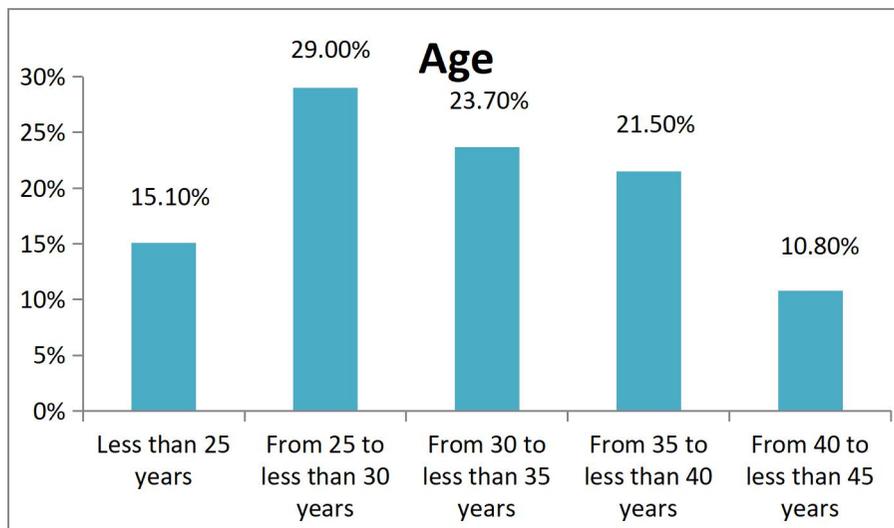


Fig (2): Percentage distribution of parents of leukemic child according to their age.

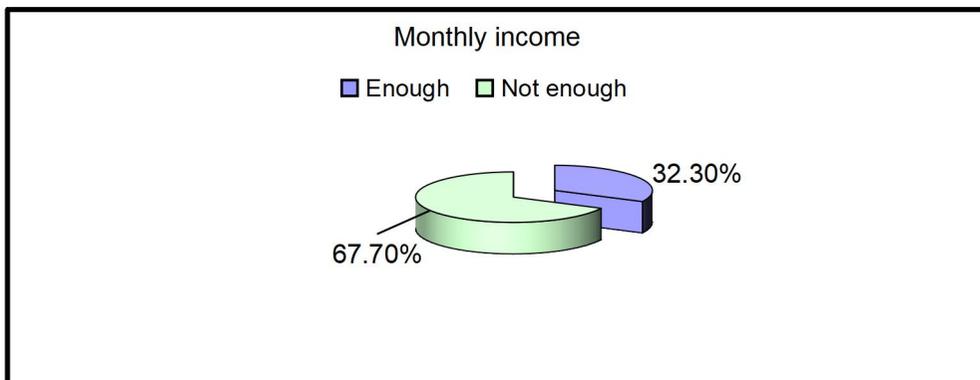
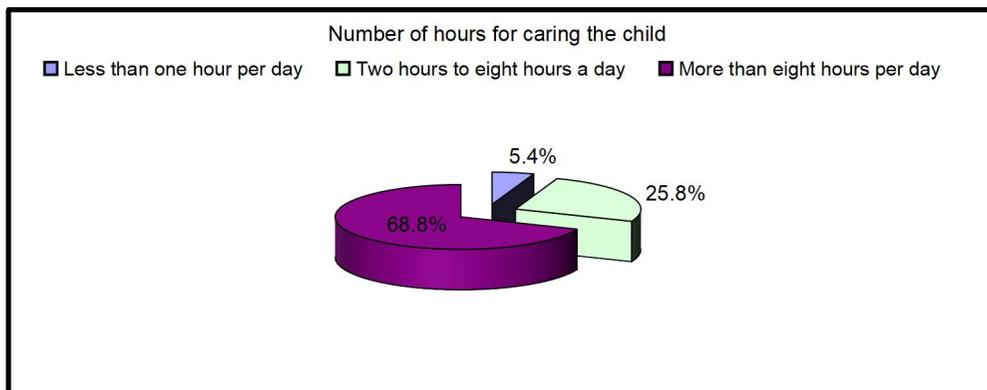


Fig (3): Percentage distribution of parents of leukemic child according to their monthly income



Fig, (4): Percentage distribution of number of hours caring for leukemic child.

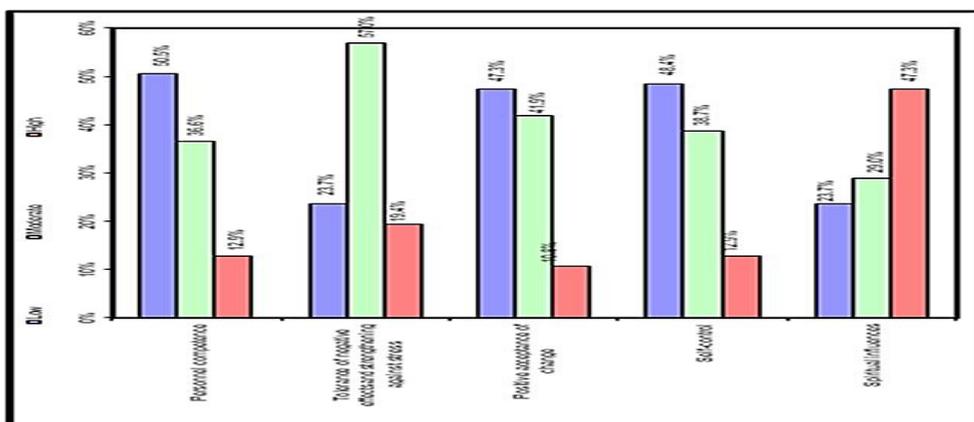


Fig (5): Percentage Distribution of levels of resilience components among parents of leukemic child.

Table (1): Distribution of Socio-Demographic characteristics of children with leukemia.

Child with leukemia		No.	%
• Sex	Male	57	61.3%
	Female	36	38.7%
• Age	< 5 years	37	39.8%
	5 < 10 years	30	32.3%
	10 < 15 years	18	19.4%
	15 < 18 years	8	8.6%
• Age at detection of leukemia	< 5 years	43	46.2%
	5 < 10 years	28	30.1%
	10 < 15 years	15	16.1%
• Period of treatment from leukemia	15 < 18 years	7	7.5%
	6months< 1 year	67	72.0%
	1 year < 2 years	16	17.2%
• Ranking of child between siblings	More than 2 years	10	10.8%
	There are no siblings	21	22.6%
	The youngest	38	40.9%
	The Middle Child	16	17.2%
	The oldest	18	19.4%

Table (2): Distribution of the total level of resilience among parents of child with leukemia.

Items		No.	%
Level of resilience among parents	• Low	33	35.5%
	• Moderate	47	50.5%
	• High	13	14.0%

Table (3): Distribution of the total level of psychological well-being among parents of child with leukemia.

Psychological well-being		No.	%
Level of psychological well-being	• Less than usual	32	34.4%
	• Same as usual	47	50.5%
	• Better than usual	14	15.1%

Table (4): correlation between resilience and psychological well-being among parents of leukemic child

	Resilience	
Psychological Well-Being	r	p-value
	0.878**	0.000

* Statistical significant difference ($P \leq 0.05$)

FET= Fisher Exact Test

Discussion

The result of the present study show that, two third of parents care-givers were housewives mothers. This reflects to the emotional bonding between mothers and their child, as well as, mothers are more able to tolerate the responsibilities of the care for their sick child and maintaining other responsibilities for the family members. This result is similar with **Danacı and Koç, (2017)**, who reported that the caregivers of oncology patients were mostly women, and especially housewives. This finding can be explained by the gender-role perceptions; as well a woman's main job within a household is to provide care for children, the elderly and people with disabilities.

The current study represents that two third of parents hadn't enough monthly income. It may be because parents face highly treatment cancer costs, besides parents give up their job to stay with the child to accomplish the needs of their child, have fewer work hours, or work from home to manage the child's demands. This result in agreement with **(Warner, et al., 2014)**, who reported that families of pediatric cancer had indirect cancer costs from treatment such as unexpected hospitalizations which cause significant financial difficulties, as well as, families may be increasingly vulnerable to financial stress related to interrupted parental employment and changes in parents' work schedules which lead to decrease their income.

The result of the current study represents that about two third of the children with leukemia were males. That is may be as indicator that the incidence of leukemia between children was large in males compared with females. This may be related to hormonal factors which increase risk factors among the children. This result accord with **Dorak and Karpuzoglu, (2012)**, in their study of "Gender differences in cancer susceptibility: an inadequately

addressed issue", who assessed the gender effect in cancer susceptibility and the methodological issues in exploration of gender differences, and reported that in leukemia, susceptibility is generally higher in males than females. Males have one copy of the X chromosome as opposed to females having two copies. If an X chromosome gene has a mutation, all male cells will lack its protein product, but 50% of female cells may still have the functional protein.

Regarding personal competence in resilience, half of parents had low level of personal competence. This may be due to different factors, parents unable to deal with complications of the treatment; they have lack of information about the caring method. Additionally, parents didn't have the skills to deal with urgent circumstances in treatment. Without knowledge, skills and training, the parents felt that they could not provide adequate and appropriate care to their child. This result is agreement with **(Given, Given & Sherwood, 2012)**, who reported that near to the half of family members had low level of personal competence. This may be related to that; family caregivers become the chief coordinator in the care of the sick family member without adequate support from the health care professionals and the society, they didn't receiving adequate information about their family member's care from the medical staff and many of them are unsure how to interpret and use the information they receive. Moreover, family caregivers have lack of training or instructions about what to do or how to do it and they were unsure about the level of quality of the care they provide. Thus, caregivers have lack of confidence and capability, and suffer from financial burdens, inadequate information, and problems in communications with health care providers.

In relation to spiritual influences, this study revealed that near to the half of parents had high levels in spiritual influences. This may be related to parents of

child with leukemia have negative experience on their lifestyle, poor social functioning, stress, uncertainty and the fear of losing their children. Spiritual influences provide a sense of meaning in life, a positive influencing on the parents' view, peace, and comfort in faith and enhance quality of life for those parents. In addition, spiritual offer reassurance and trust in merciful of the God and the perspective of benefit derived from overcoming suffering that is result from the caregiving. This result is in the same line with **Vitorino, et al., (2018)**, who reported that three-quarter of family caregivers were practicing spiritual and religious coping techniques who did not present depressive symptoms, and only negative Spiritual and religious coping remained associated with depressive symptoms of family caregivers of pediatric cancer patients. Caregivers who find spiritual meaning in the care situation develop a buffer that sustains their psychological well-being, which may protect them from the aversive effects of caregiving stress.

The result of the present study shows that half of the parents had moderate levels of resilience. This may be related to different reasons: adequate emotional and support provided from the social services in the hospital, income and financial stability for some parents; increased parental knowledge through education from nurses, interacting with parents having a child with the same diagnosis, and finally, religion, prayer and faith in God were contributors in raising resilience level among parents. This study is consistent with **Katooa, (2014)**, in his study of "Resilience of Saudi families with chronically ill children", who assessed the factors that contributing resilience of Saudi parents when faced with the adversities of chronically ill children and the relationships between family resilience and a chronic illness of a sick child, and reported that parents had moderate levels of resilience.

As regards to Purpose in life in psychological wellbeing of parents, the result of present study show that two third of parents had low level in purpose of life because parents hadn't future plans, they didn't know the purpose of life and their daily activities didn't help them achieving their goals. This may be related to fear from losing their child, they didn't receiving the appropriate assistance from the social services, social isolation, loss sense meaning of the life and uncertainty of the future. This result is congruent with **Ciro and Liliana, (2012)**; who reported that the majority of parents had low level in purpose of life. This may be related to anxiety, fear and frustration related to the future of the child and uncertainty of the condition.

The results of the present study show that half of parents had psychological well-being same as usual. This may be due to the most of parents have been adopted with demands of the child illness due to availability of social support within hospital services and providing information about the disease through continued education which enhance their self-efficacy, in addition, parents relying on the God to facilitate everything in their lives. This result is accord with **Kim and Shin, (2017)**; they assessed positive and negative aspects of the caregiver reaction and identify factors influencing psychological well-being among family caregivers of cancer patients, and reported that more than half of caregiver of cancer patients had moderate level of psychological well-being.

The current study results represent that there is a positive significant correlation between psychological well-being and resilience among parents of leukemic child regarding Personal competence. This is related to personal competence increases the ability to take care for their child successfully, efficiently and perform the care to a high level of performance, moreover, it improve knowledge to

negotiate function and deal effectively with the stressful situations. Hence, personal competence leads to increase parents' levels of psychological wellbeing. This result accord **Rosenberg, et al., (2013)** in their study of "Promoting resilience among parents and caregivers of children with cancer", reported that personal competence improve the family well-being, this is related to competency increase the caregiver's ability in planning and making decisions, problem solving, managing behavioral problems and complying with social rules, as well as emotional and stress management.

The current study results represent that there is a highly positive significant correlation between resilience and psychological well-being. This may due to different factors, parents have been accepted the diagnosis of their child and its complications by using different coping methods, facing many urgent conditions during treatment which lead to tolerance of caregivers and responsibility, in addition, they have been a faith in God to support them, finally they have been satisfied with the what was happen to their child. As consequence, resilience has a strong power for positive affect, followed by satisfaction with life and promotes the psychological wellbeing of the parents. This result is congruent with **(Le, 2011)**, who assessed the relationship between resilience and mental health, and reported there is a positive relationship between resilience and the psychological well-being which enhance the mental health. This is related to resilience among parents are better in maintaining their psychological health which gives them more power to recover easily and quickly from stressful situations, gives parents a better confidence, sense of self and empowers them to deal effectively with the negative emotions, and thus, it plays an important role in their psychological well-being.

Conclusion

The current study results revealed that there was positive significant correlation between resilience and psychological well-being among parents of child with leukemia. Ultimately, these results may assist the research in Psychiatric Health Nursing department to design interventions that influencing resilience among parents of child with leukemia.

Recommendations

In the light of the findings obtained from the present study, the following suggestions are recommended:

- Development of stress management and resilience training programs to decrease stress and enhance resilience among parents of child with leukemia.
- Assessing the factors that influencing resilience among parents of child with cancer.
- Establishment of counselling clinic to enhance resilience among parents of child with cancer.
- Future research to assess burdens, resilience and psychological well-being among parents of a child with cancer in the hospice care.

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