

Psychological Burden of Caregivers of Children with Cancer at AL-Amal Hospital in Baghdad City

Ahmad Shihab Ahmad

Ph.D. of Community Health Nursing Science/ALZahrawi College University

Abstract

Objectives: To assess psychological burden of care givers of child with cancer at Al-Amal Hospital in Baghdad City

Method: Descriptive study conducted among 50 caregivers, they are using self-administration method to answer the psychological burden items. The data collection started from October 7th 2019 to March, 9st 2020 at Al-Amal Hospital in Baghdad city.

Results: 50% of caregivers had moderate level of psychological burden and 44% had severe level of psychological burden. The grand mean was (2.21) at moderate level of assessment. There is no significant relationship between the caregivers psychological burden and their general information at P-value 0.05.

Conclusion: The care giver had moderate to severe psychological burden due to caring child with cancer. They are need for psychological support.

Keywords: *Psychological Burden, Caregivers, Children, Cancer.*

Introduction

Cancer is expected to rank as the leading cause of death and the single most important barrier to increasing life expectancy in every country of the world in the 21st century. According to estimates from the World Health Organization (WHO) in 2015, cancer is the first or second leading cause of death before age 70 years in 91 of 172 countries, and it ranks third or fourth in an additional 22 countries.⁽¹⁾ 'Burden' may be defined as a multidimensional concept with objective and subjective components. 'Objective burden' is defined as specific happenings and activities related to caregiving, for instance, financial problems or personal activity limitations. 'Subjective burden', on the other hand, encompasses affective responses to the caregiver experience, such as feelings and emotions related to fear, strain and guilt.⁽²⁾ Family caregivers (FCs) are a pivotal source for quality of life, well-being and quality of care in terminally ill patients. However, they are also affected by caring for the patient and may thus be affected by significant physical and psychosocial burden. Psychosocial burden and anxiety are associated with the number of unmet needs in FCs of advanced

cancer patients. Frequently unmet needs of FCs relate to information on caregiving and care planning, support in managing fear as the patient's physical or psychological status declines, and preparing for the patient's death and their own bereavement. Supportive needs can be summarized in four main categories: needs concerning the patient's well-being, transfer of information, practical problems of caregiving, and emotional support. Some studies suggest that FCs' needs might be better addressed if specialized palliative care is included during home or hospital care. In addition, FCs' quality of life has been shown to be higher in patients receiving care in palliative care facilities rather than in acute care hospitals.⁽³⁾ Cancer is a family experience, and often family members have as many problems coping with it as does the diagnosed patient. The family goes through different stages of adjusting to the disease. The emotional reactions may include anger, resentment, guilt and adjustment pain, and may or may not lead to the acceptance of the disease. The cancer's diagnosis, as well as the subsequent phases of the disease and its treatment, may be a source of intense stress both for the patient and for the family. Patients and their relatives need to

face the challenge of a life defined with uncertainty; treatment routines, the threat of recurrence or the failure of the treatment.⁽⁴⁾

Caring for a child with cancer can be profoundly distressing to parents and in turn, parental psychological distress (PD) can affect child and sibling wellbeing. Caring for a child with advanced cancer is likely to be even more distressing, yet very few prospective studies have evaluated parent PD among these families. Understanding the degree of PD and contributing factors among parents with children with advanced cancer has the potential to better enable clinicians to identify higher risk families and optimize outcomes.⁽⁵⁾

Family caregivers often feel overloaded with the additional obligations and roles they have to pick up. They find it increasingly burdening to care full-time for the household and provide emotional support for the patient. The family's problems and the way family members regard the disease may be also a result of the family system they are in.⁽⁶⁾

The role of a family in the course of cancer changes according to the needs of the patient and the cancer's phase. In the diagnosis phase, depending on the type of family, a big mobilization, with readiness to give support to the patient, is observed. Family members try to get information about the diagnosis, treatment and chances of survival. Other family types may avoid talking about the cancer to avoid creating an additional stress for the patient. Also, very often both the patient and family members try to search for the reasons for the sickness. Looking to find some sense in the universe is a very common tendency, which results from the conviction that everything in the world has its place and reason. Depending on the family's coping style, if it is a task concentrated family, attitude towards the sickness may

promote healthy behavior or strengthen the will of the patient to fight.⁽⁷⁾

Taking care of a sick patient, most caregivers share some common needs which unfortunately are not always possible to be fulfilled. All of them have a need for information, for feeling close to and needed by the patient, and to have a chance to get external support whereby they can speak about their own problems – to 'ventilate' their emotions.⁽⁸⁾

Method

Descriptive study design was conducted to assess psychological burden of care givers of child with cancer at Al-Amal Hospital. The data collection started from October 7th 2019 to March, 9st 2020 at Al-Amal Hospital in Baghdad city. The study carried among 50 caregivers selected by a non-probability (purposive sample). The study tool was used constructed questionnaire tool psychological burden of care givers of child with cancer. The questionnaire consists of two parts:- Demographic data of sample composed of (5) items that represent the sample demographic data such Age, gender, level of Education, relative to the child and socio economic status and the psychological burden consisted from 14 items constructed to measure the phenomena, rating and scoring according to 3 likert scale answered by 3 key answer always (3), sometimes (2) and never (1), which assessed by cutoff point (0.66) due to scores (1, 2 and 3) respectively. level of assessment: (1-1.66) = low = L, (1.67-2.33) = moderate = M, (2.34-3.00) = severe = S. The data collected after taken the sample agreement to participate in the study and using self-administration method to gathering data. The data analysis by using descriptive and inferential data analysis (SPSS version 20).

Results

Table (1): Distribution of the study sample by their general information

Variables		Frequency	Percent
Age	19-28	9	18
	29-38	14	28
	39-48	18	36
	49 and more	9	18
	Total	50	100

Variables		Frequency	Percent
Gender	Female	28	56
	Male	22	44
	Total	50	100
Educational level	Read and write	3	6
	Primary school graduate	8	16
	Elementary school graduate	18	36
	Secondary school graduate	12	24
	Diploma and bachelor graduate	9	18
	Total	50	100
Relative person	Father	22	44
	Mother	22	44
	Sister	6	12
	Total	50	100
Socio economic status	Insufficient	10	20
	Barely sufficient	21	42
	Sufficient	19	38
	Total	50	100

This table shows that 36 % of them at age 39-48 years old. 56% of them were females. 36% of them were elementary school graduated. 44% of them were fathers and mothers of children. 42% of them had barely sufficient of socio economic status

Table (2): Distribution of the psychological burden of caregivers

No	Items	Always	Some times	Never	Mean	Ass.
1	We got insomnia because of our affected child	25	17	8	2.34	S
2	We feel guilty especially when our child suffers from the disease	30	16	4	2.52	S
3	We have a desire to cry because of the disease of our affected child	21	17	12	2.18	M
4	We are scared about the future of our affected child	19	16	15	2.08	M
5	We are hopeless that our child getting cured	5	13	32	1.46	L
6	We panic when heard about death of other affected child	11	8	31	1.60	L
7	We are hesitated from having other children because of the disease	42	8	-	2.84	S
8	We feel despair of our child because he could not share playing with his mates	20	17	13	2.14	M
9	We feel incomplete because of the disease	34	10	6	2.56	S
10	We feel despair of our child because he has to keep away for long times from his mates	20	18	12	2.16	M
11	We feel pain for his long time of because from school because of his disease	18	15	17	2.02	M
12	We feel pain because of his growth retardation because of the disease	18	14	18	2.00	M
13	We feel grief on our affected child because of his deformity of shape by the disease	39	8	3	2.72	S
14	We feel pain when we see our child not able to eat all types of food	30	11	9	2.42	S
Grand Mean		2.21		Assessment		Moderate

M= mean, Ass.= assessment, level of assessment: (1-1.66) = low = L, (1.67-2.33) = moderate = M, (2.34-3.00) = severe = S

This table shows that when the care givers response to the burden questionnaire, they had moderate psychological burden the grand mean was (2.21) at moderate level of assessment

Table (3): Caregivers level of psychological burden

Level of Burden	Frequency	Percent
Low level (1-1.66)	3	6
Moderate level (1.67-2.33)	25	50
Severe level (2.34-3)	22	44
Total	50	100

This table shows that 50% of caregivers had moderate level of psychological burden and 44% had severe level of psychological burden

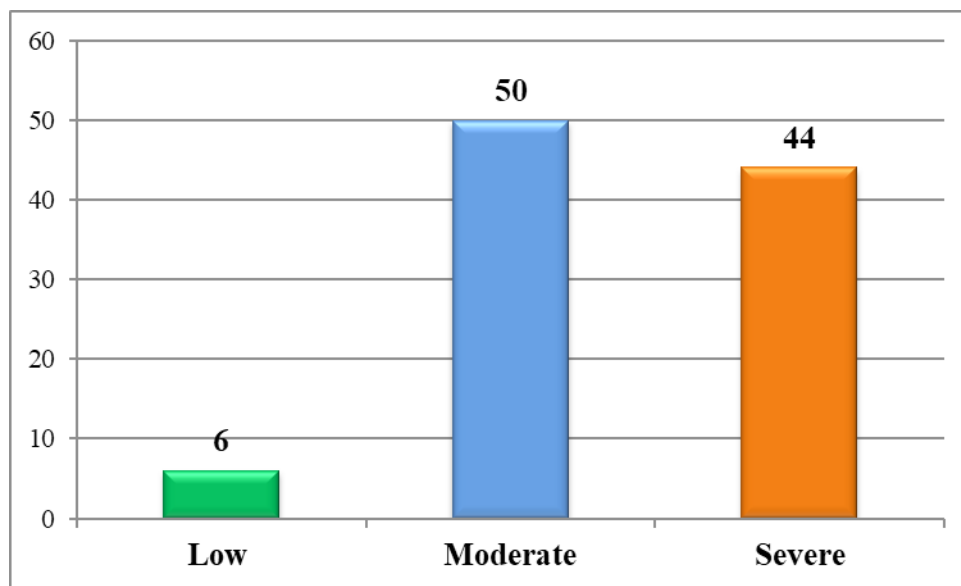


Figure (1): Psychological burden of caregivers for child with cancer

Table (4): Multiple regression of the caregiver burden with their general information

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	2.477	.422	-	5.872	.000
Age	.026	.052	.076	.503	.617
Gender	-.171	.152	-.251	-1.127	.266
Education	.058	.045	.193	1.295	.202
Relative person	-.116	.080	-.321	-1.456	.153
Socioeconomic status	-.030	.070	-.065	-.425	.673

Significant level at $P \leq 0.05$, (b=beta) Regression Coefficient, (t) test the significant of regression equation, S=significant, HS = high significant, NS= non-significant

There is no significant relationship between the caregivers psychological burden and their general information at P-value 0.05.

Conclusion

Parenting a child with advanced cancer is strongly associated with moderate to severe levels of psychological burden. Interventions aimed at aligning prognostic understanding with concrete care goals, and easing child suffering and financial hardship may mitigate parental psychological burden. Suggestions for further research are presented to support efficient psychosocial interventions and minimize the psychosocial problem experienced by pediatric caregivers over the course of onco-hematological treatments.

Financial Disclosure: There is no financial disclosure.

Conflict of Interest: None to declare.

Ethical Clearance: All experimental protocols were approved under the ALZahrawi College University and all experiments were carried out in accordance with approved guidelines.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel R. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*. 2018; 68(6): 394–424
2. Bastawrous M. Caregiver burden – a critical discussion. *Int J Nurs Stud*. 2013; 50: 431–441
3. Ullrich A, Ascherfeld L, Marx G, Bokemeyer C. Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC palliative care*. 2017; 16(1): 31.
4. Ljungman L, Hovén E, Ljungman G. Does time heal all wounds? A longitudinal study of the development of posttraumatic stress symptoms in parents of survivors of childhood cancer and bereaved parents. *Psychooncology*. 2015; 24: 1792–1798.
5. Rosenberg A, Dussel V, Kang T. Psychological distress in parents of children with advanced cancer. *JAMA pediatrics*. 2013; 167(6): 537–543.
6. Woźniak K, Iżycki D. Cancer: a family at risk. *Przegląd menopauzalny = Menopause review*. 2014;13(4): 253–261.
7. Kearney JA, Salley C, Muriel A. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015; 62(5): S632–683
8. Ljungman L, Cernvall M, Grönqvist H. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PloS One*. 2014; 9: e103340.